

**Federal Commission on Long-Term Care**

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

***What would strengthen Medicaid Long-Term Services and Supports?***

**Thursday, August 1, 2013  
Dirksen Senate Office Building, SD-562  
Washington, DC**

Medicaid is today a mainstay of long-term services and supports (LTSS) in both the community and in institutions for a diverse and very high-need low-income population. My testimony today will focus on the population Medicaid serves today, the role Medicaid plays in our long-term care systems, and the gaps and potential improvements in the assistance Medicaid provides to individuals of all ages.

**Medicaid Long-Term Care Beneficiaries**

The Medicaid long-term care beneficiary population is exceedingly diverse in terms of the demographic composition, the array of daily health care needs, and the availability of informal caregiving supports in the community. What is not diverse is the need for assistance due to ongoing and persistent cognitive and physical impairment and chronic conditions that result in the need for assistance with the activities of daily living and the lack of adequate income and resources to secure the required assistance.

In 2010, 3.8 million individuals accessed Medicaid long-term services and supports at a cost of \$159 billion. Slightly more than half of users were over age 65, 43 percent qualified for Medicaid as individuals with disabilities, and 6 percent were non-disabled adults and children

(Figure 1). Much attention recently has been focused on Medicaid's role for those dually entitled to Medicare and Medicaid. In 2010, 69 percent of Medicaid beneficiaries (both under and over age 65) using long-term care services were dually eligible and accounted for 64 percent of total Medicaid LTSS spending.

Medicaid coverage of long-term care includes an array of services and supports that assist individuals with performing daily health and personal care activities. Depending on an individual's need, these activities range from providing assistance with eating, dressing, and toileting, to assisting with household chores or managing prescription medications. Medicaid covers a continuum of long-term care service settings. While many prefer to remain in the community, some individuals with extensive needs require nursing home care.

#### Medicaid's Role Today

With limited coverage options available under Medicare and few affordable options in the private insurance market, Medicaid continues to be the primary payer for institutional and community-based services and supports. But, Medicaid is a means-based entitlement requiring people to meet both an income and disability test to obtain assistance. To qualify an individual must be totally and permanently disabled or over 65 with significant cognitive and physical limitations, have limited income, and few personal assets. Although there is variation in the eligibility rules across states, to receive Medicaid assistance with long-term care essentially requires impoverishment -- which is often the result of ongoing health and long-term care needs.

Two myths persist about Medicaid and long-term care. The first is that large numbers of long-term care users qualify for Medicaid by transferring their assets to gain coverage. The

reality is that few senior citizens and people with disabilities have large sums of assets to transfer -- a Kaiser Family Foundation study found that most frail seniors who receive Medicaid benefits were poor prior to enrollment and that when individuals did make transfers, the amount of assets transferred by those individuals was, on average, small (one-half of study participants had asset (cash and deed) transfers of less than \$5,000). Additional studies have confirmed these findings. The second myth is that once eligibility for Medicaid assistance for institutional care is obtained, Medicaid pays the full bill. In reality, Medicaid requires that beneficiaries continue to contribute available income (from pensions and Social Security) toward the monthly cost of their care and allows individuals to retain only \$60 a month as a personal needs allowance while institutionalized.

The problem that most Americans encounter when they or a loved one needs long-term services and supports is that such care is unaffordable. Annually, nursing home care averages more than \$80,000, care in an assisted living facility over \$40,000, and home health care over \$21,000. It is hard to save for such significant and often unpredictable expenses and it's hard for elderly Americans living on Social Security and barely getting by to be able to afford the cost of ongoing long-term care. A Kaiser Family Foundation national study found that nearly half of all seniors (48%) live with incomes below 200 percent of the poverty threshold (approximately \$21,000).

Medicaid continues to be the long-term care safety net for millions of Americans because there are few other alternatives. In 2011, the nation spent \$357 billion on long-term services and supports with Medicaid covering 40 percent (or \$143 billion). Medicare's post-

acute benefit picked up 21 percent, other public and private providers 18 percent, private insurance 7 percent, and personal out-of-pocket payments 15 percent (Figure 3).

Medicaid has also increasingly shifted the balance in long-term care services and supports from heavy reliance on institutional care to much greater availability of home and community-based care that allows the elderly and people with disabilities to live at home and among their support networks (Figure 4). The share of spending on long-term care for community-based services has grown from 32 percent in 2002 to 45 percent in 2011 due in part to the U.S. Supreme Court *Olmstead* decision that mandated the availability of integrated, community-based care alternatives to nursing homes for beneficiaries. There is considerable variation among states in the share of Medicaid long-term care dollars spent on home and community-based services, with the national average close to 45 percent (Figure 5).

The *Olmstead* case and the push for community-care settings has been particularly important for individuals under age 65 with disabilities. Half of elderly long-term care users rely on Medicaid for institutional care compared to 21 percent of non-elderly individuals with disabilities who used long-term care services (Figure 6). For non-elderly beneficiaries with disabilities, community based care accounts for 63 percent of total expenditures whereas for the elderly 72 percent of spending on long-term care is for institutional care.

New models of care delivery and greater focus on community-based care in Medicaid have helped to provide an alternative to institutional care that has been especially important for the younger adults with disabilities. Community caseworkers are critical to the ability of many to live in the community and coordinate their care needs; Medicaid's Money Follows the

Person, or “MFP,” demonstration enables institutionalized individuals to transition to the community.

The experiences of Medicaid beneficiaries Kelli, Don, and Edward from interviews conducted as part of a Kaiser Family Foundation study reflect the importance of having strong community-based options in Medicaid and also reflect the importance of keeping institutional care as a last not first option.

***Kelli, Age 64, Oklahoma (Dually Eligible Beneficiary)*** - Kelli does not have any family or friends that she can turn to for help and support. Kelli says that her mental illness makes it difficult for her to make friends and trust people, yet she was able to establish a close relationship with her Medicaid caseworker. Having her caseworker's assistance has made such a positive difference for Kelli because, as she says, in regard to managing her care, "It can be very complicated because my mind just doesn't function like it used to anymore." With assistance, Kelli is about to live independently in the community and feels in control of her life.

***Don, Age 41, Michigan (Dually Eligible Beneficiary)*** - Don was born with developmental disabilities. With help of his legal guardian, Don qualified for self-directed Medicaid in-home services; he enjoys having the freedom to allocate his Medicaid dollars for approved services. Don uses most of these dollars to hire his own caregivers. Having caregivers who he trusts greatly improves Don's quality of life. He wishes to remain in the community and live independently.

**Edward, Age 64, Georgia (Medicaid Beneficiary)** - Edward lives independently now, following three years in nursing homes after he lost both legs to an infection. Edward's goal was always to live again on his own, and he was able to make this transition through Georgia Medicaid's Money Follows the Person program. Money Follows the Person helped Edward find affordable housing and connected him with health care providers in the community. Medicaid also covers homemaker and meal services a few hours each day and pays for the power wheelchair that enables Edward to grocery-shop and get around town. Edward shared, "I really wanted to leave the nursing home, but was told there were no funds to help me. Then a social worker came and told me about MFP."

### Challenges Ahead

As the baby boomers age into older adulthood with increased life expectancy and advances in medical care, we can expect the demand for long-term services and supports --- especially in the community --- to increase in the coming decades (Figure 7). Those age 85 and over -- the age cohort most likely to need long-term services and supports is expected to increase by almost 70 percent in the next 20 years. The time for addressing this population dynamic and the stress it will put on services and financing is now --- while we have the ability to find new and more efficient and effective ways to deliver and finance high quality care for both today's seniors and people with disabilities and to plan for the demands the future will bring.

With the passage of the Affordable Care Act, states are afforded a number of new and expanded opportunities, including enhanced federal financing, to improve access to and

delivery of Medicaid long-term services and supports. To date, nearly every state (47 states and DC) has taken steps forward with at least one of the six key options, with the Money Follows the Person demonstration being the most popular option (45 states and DC) (Figure 8). Many states are pursuing or plan to pursue additional new LTSS options however budget constraints and administrative complexities have limited their potential.

CMS reports that more than half the states are expected to be operating capitated Medicaid managed LTSS programs by January 2014, including the expansion of current Medicaid capitated managed LTSS programs, establishment of new Medicaid capitated managed LTSS program, and implementation of Medicare/Medicaid financial alignment demonstrations for dual eligible beneficiaries. While these offer the prospect of more integrated and comprehensive care, establishing the appropriate capitation rate and broader provider networks for these complex populations is a challenge.

Strengthening Medicaid's role as a source of care and financing for people with disabilities, is a key element of building a strong foundation for assuming that long-term services and supports are available and accessible to those in need. Some areas for reform the Commission should consider include:

**#1** – Development of a “single point of entry” information and referral system where individuals with long-term care and their advocates can obtain information about services and supports in an accessible, easy-to-understand format, greater uniformity in eligibility criteria and the scope of services across

states, and the implementation of a validated universal assessment tool for level of care determinations to facilitate more consistent coverage across states

**#2** – Streamline the new and expanded ACA home and community-based long-term services and supports options into a comprehensive optional state plan benefit for all states with broader federal support. Today fewer than half the states have taken up the Balancing Incentive Program (18 states) or the Community First Choice state plan option (10 states) or the home and community-based services state plan option (14 states), and the popular Money Follows the Person demonstration is set to expire in 2016.

**#3** – Development of ways to enhance community-based supports for individuals with cognitive impairments and improving the integration of behavioral health and medical care to provide care coordination in the community.

**#4** – Improvement of the quality of care in institutional and community-based settings and the development standard outcomes metrics that can be tied to performance and provide payment incentives for quality.

**#5** – Widespread recognition that care improvement and the provision of additional community-based resources will require increased funding and broader incentives at a time of severe budgetary constraints. Cuts to Medicaid and reduced funds will impede not promote ways to improve quality and access to care for this population.

Medicaid is today and will probably remain a cornerstone of our nation's approach to providing assistance to the elderly and people with disabilities who need long-term services and supports for the foreseeable future. We need to invest and strengthen the capacity of Medicaid to meet the needs of today's population and, in the absence of broader changes, prepare for future demands.

*<End of Testimony>*