Issues in Missouri Health Care 2011

Meeting the Needs of Missourians Who Are Elderly or Have Disabilities: Long-Term Care

Acknowledgement

This is one in a series of issue papers on critical health care issues facing Missouri and the nation prepared by Health Management Associates, Inc., a national health care policy research and consulting firm, and made possible by funding from the Missouri Foundation for Health and the Healthcare Foundation of Greater Kansas City. The papers are intended to provide nonpartisan expert analysis in an accessible format that will contribute to the public dialogue on the state of health care in Missouri. Questions should be directed to Thomas McAuliffe, Policy Analyst, Missouri Foundation for Health, 314.345.5574, tmcauliffe@mffh.org.

Issue Statement

One of the driving forces behind the projected increased demand for long-term care services over the next 10 years is the aging of Baby Boomers.[1] In 2010, approximately 15 percent of Missouri's population was 65 years of age or older. By the year 2020, Missourians aged 65 and older are projected to be more than 18 percent of the population.[2]

Most individuals prefer to receive long-term care services in their own homes or in a community-based residential setting rather than a nursing home. Meeting this growing demand poses significant policy and financial challenges for Missouri in the years ahead.

Background

What is Long-term Care?

The U. S. Senate Special Committee on Aging prepared a report that described long-term care:

> It [long-term care] differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning…Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.[3]

Who Needs Long-Term Care?

Persons in need of long-term care have physical, developmental, or mental limitations or disabilities.[4] Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks. These are called activities of daily living (ADLs) such as bathing, dressing or eating; or instrumental activities of daily living (IADLs) such as household chores, meal preparation, or managing money. Most, but not all, Missourians in need of long-term care are elderly (63%), and the balance are under age 65 and have a disability. Nationally, long-term care services and supports are used by elders (55%), persons under age 65 with physical disabilities (27%), persons with developmental disabilities (15%) and persons with chronic mental illness (3%).[5]

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1 The term "Baby Boomer" describes a person born between 1946 and 1964.

2 Missouri Department of Health and Senior Services. (September 27, 2007). *Missouri State Plan on Aging (Fiscal Years 2007 through 2011).* Accessed October 4, 2010. Retrieved from http://www.dhss.mo.gov/SeniorServices/MOStatePlanonAging2007-2011.pdf.

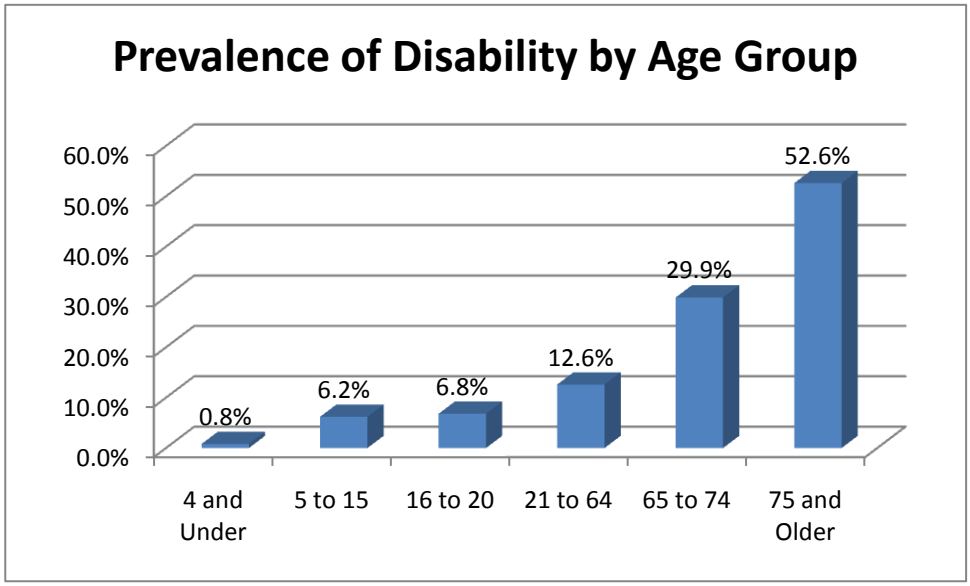
3 United States Special Senate Subcommittee on Aging. (February 13, 2000). *Developments in Aging: 1997 and 1998, Volume 2.* Accessed October 4, 2010. Retrieved from http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=106_cong_reports&docid=f:sr229v2.106.

4 Family Caregiver Alliance. (2005). *Fact Sheet: Selected Long-Term Care Statistics*. Accessed October 4, 2010. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=440.

5 Mathematica Policy Research, Inc. (September 24, 2005). *Current Status and Policy Implications of the Money Follows the Person Demonstration.* Accessed October 4, 2010. PowerPoint Presentation retrieved from http://www.disabilitypolicyresearch.org/Forums/20090924/combined.ppt.

In 2008, approximately 14 percent of non-institutionalized Missourians (817,900) identified themselves as having a disability.[6] More than four percent of Missourians identify themselves as having difficulty with self-care or independent living. The prevalence of disability by age in Missouri is:

Figure 1.



Where Is Long-Term Care Provided?

According to national estimates, 79 percent of all people who need long-term care live at home or in community residential settings rather than in nursing homes or other institutions.[7] Three quarters of adults living at home or in the community receive care from family and friends alone; 14 percent receive a combination of care from family, friends and formal caregivers; and only eight percent receive all of their care from a formal caregiver.[8]

The Cost of Long-Term Care

In 2006, the total cost of paid long-term care in the United States was $206.6 billion,[9] while another $375 billion was provided by informal caregivers.10 State Medicaid programs are the

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6 Erickson, W. Lee, C., & von Schrader, S. (2010), *2008 Disability Status Report: Missouri.* Cornell University Rehabilitation Research and Training Center on Disability Demographics and Statistics. Accessed October 4, 2010. Retrieved from http://www.ilr.cornell.edu/edi/disabilitystatistics/reports/report.cfm?fips=2029000.

7 Family Caregiver Alliance. (2005). *Fact Sheet: Selected Long-Term Care Statistics*. Accessed October 4, 2010. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=440

8 Administration on Aging. (September 9, 2004). *NFCSP Complete Resource Guide.*

9 U.S. Department of Health and Human Services. (May 12, 2010). *National Clearinghouse for Long-Term Care Information.* Accessed October 4, 2010. Retrieved from http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx.

10 AARP Public Policy Institute. (November 2008). *Valuing the Invaluable: The Economic Value of Family Caregiving 2008 Update.* Accessed on October 5, 2010. Retrieved from http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf.

largest payer of long-term care services. Missouri's Medicaid spending on long-term care was $1.9 billion in 2009:

- 69% for nursing homes;
- 22% for personal care services and other home and community-based care; and
- 9% for care received through Missouri's aged/disabled waivers.

The Medicaid expenditures for long-term care services between 2004 and 2009 are summarized in Table 1:

Table 1. Medicaid Long-Term Care Expenditures by Service

Services	FY 2004 Expenditures	FY 2009 Expenditures	Percent Change 04-09
Nursing Home Services	$795,296,327	$870,160,260	+9.4%
ICF-MR	$257,058,881	$152,896,442	-40.5%
Personal Care	$208,873,425	$317,985,287	+52.2%
HCBS Waiver-DD	$275,243,221	$425,055,086	+54.4%
HCBS Waiver- A/D	$88,104,658	$113,137,245	+28.4%
Home Health	$5,715,948	$5,520,214	-3.4%
Programs for All-Inclusive Care for the Elderly (PACE)	$5,317,242	$5,243,836	-1.4%

Source: Eiken, S., Sredl, K., Burwell, B., and Gold, L. (August 17, 2010). *Medicaid Long-Term Care Expenditures in FY 2009*.

In addition to these expenditures, there are approximately 590,000 Missourians who are providing care to a family member or friend. The uncompensated value of this care is estimated to be more than $6 billion.[11]

11 Gibson, M., Fox-Grage, W., and Houser, A. (2009). *Across the States 2009: Profiles of Long-Term care and Independent Living.* Access October 4, 2010. Retrieved from http://assets.aarp.org/rgcenter/il/d19105_2008_ats.pdf.

Promoting Choice, Providing Options

While the overwhelming majority of people would prefer to stay in their own homes if they need long-term care services, the type and availability of long-term care are largely a reflection of the programs and services for which the federal and state governments are willing to pay. Historically, federal Medicaid reimbursement has favored care in institutions such as nursing facilities and state hospitals, rather than care that can be delivered in the individual's home or in another community-based setting such as adult day care.

In a 2005 member survey of Missourians,[12] AARP found that:

- Six in ten were worried about not having their choice of long-term care services.
- Eighty-five percent had a preference to receive long-term care in their own homes or in a home-like setting. Only three percent wanted to go to a nursing home.
- More than half would be more likely to vote for a candidate who supports shifting funds from nursing homes to long-term care services that help people stay in

Through various federal and state initiatives, including the increased opportunities for states to seek Medicaid Home and Community-Based Services (HCBS) waivers and various grants, the design of long-term care programs and services has begun to shift away from paying for institutional care, and toward home and community-based care.[12] Table 2 provides a list of Missouri's Medicaid waivers. Under these waivers, home and community-based care is not only delivered in a preferred setting, but also offers the potential of lowering per person costs. The term most commonly used for this shift in site and cost of care is "rebalancing."

12 Gibson, M., Fox-Grage, W., and Houser, A. (2009). *Across the States 2009: Profiles of Long-Term care and Independent Living.* Access October 4, 2010. Retrieved from http://assets.aarp.org/rgcenter/il/d19105_2008_ats.pdf.

Table 2. Missouri Medicaid HCBS Waivers and Expenditures

Target Population (Waiver Number)	FY 2004 Expenditures	FY 2009 Expenditures	% Change
Aged/Physical Disability Age 63+, meet NH level of care (0026)	$83,571,255	$102,907,223	+23.1%
Developmentally Disabled - incl. Intellectual Disability & Autism Spectrum Disorder Developmental disability requiring care in an ICF/MR (0178)	$273,669,066	$416,065,836	+52.0%
HIV/AIDS AIDS/HIV diagnosis (0197)	$302,275	$2,308,374	+663.7%
Aging/Physical Disability Age 18-64, physical or cognitive disability, NH level of care (0346)	$1,851,527	$2,167,133	+17.0%
DD – incl. Intellectual Disability and Autism Spectrum Disorder Developmental disability requiring care in ICF/MR (0404)	$1,574,155	$8,989,250	+249.2%
Aging/Physical Disability* (0649)	$0	$0	N/A
Autism Spectrum Disorder* (0698)	$0	$0	N/A
DD - (Lopez Waiver) Age 0-18, total developmental disability (40185)	$270,844	$924,274	+241.3%
Physical Disability Age 21+, physical disability (40190)	$2,681,876	$8,062,889	+200.6%
Total for all Waivers	$363,920,998	$541,424,979	+48.8%

* These two waivers were effective in FY 2009; no expenditure data were reported at the time of this article.

Source: Eiken, S., Sredl, K., Burwell, B., and Gold, L. (August 17, 2010). *Medicaid HCS Waiver Expenditures FY 2004 through FY 2009*.

Missouri was an early innovator in reforming its long-term care system and providing choice to Medicaid recipients.[13] Missouri Care Options, implemented as a result of legislation enacted in

13 Missouri Department of Health and Senior Services, Division of Senior Disability Services. (September 19, 2007). *Missouri State Plan on Aging.* Access October 4, 2010. Retrieved from http://www.dhss.mo.gov/SeniorServices/MOStatePlanonAging2007-2011.pdf.

1992, focused on shifting the care from institutional settings and encouraging the development of a fuller continuum of home and community-based options; improving the opportunity to receive care in the least restrictive setting; improving the coordination of care; and providing an improved quality of life. Table 3 shows the progress that Missouri has made to expand access to home and community-based options. It is also significant to note that the number of people served in nursing homes has remained flat while, according to the U.S Census Bureau, the population over age 65 in Missouri increased 12 percent.

Table 3. Missouri Progress in Expanding Access to HCBS

Type of Service	Medicaid Participants			Expenditures (millions)		
	1999	2004	Percent Change	2001	2006	Percent Change
HCBS	57,407	73,160	+21.5%	$228	$320	+28.8%
Nursing Homes	39,762	39,606	-0.4%	$726	$763	+4.8%

Source: Kassner, E., et al. (July 2008). *A Balancing Act: State Long-Term Care Reform.* AARP Public Policy Institute.

Over the past eleven years, there have been other events, initiatives and funding opportunities that have contributed to this shift.

- In 1999, the U. S. Supreme Court issued an interpretation of the Americans with Disabilities Act (ADA), stating that persons with disabilities have the right to receive care in the most integrated setting appropriate to their needs and that unnecessary institutionalization violates the Act. Following President George W. Bush's order of June 2001, which directed federal agencies to assist states in developing plans to comply with the Court's decision, Missouri developed an Olmstead Plan under the auspices of the Governor's Council on Disabilities.[14]
- In 2005, the Missouri Department of Mental Health received a $2.97 million, 5-year federal Medicaid System Transformation Grant to fund community-based care options for persons with developmental disabilities needing long-term care.[15] The grant program was made possible by President George W. Bush's 2001 "New Freedom Initiative."
- In 2006, Missouri was awarded a Mental Health Transformation State Improvement Grant to assist the state in transforming its public mental health system to one driven by consumer/family

14 Center for Personal Assistance. (August 2009). *The 1999 Olmstead Supreme Court Decision and Missouri.* Accessed October 4, 2010. Retrieved from http://www.pascenter.org/state_based_stats/olmstead_home.php?state=missouri.

15 Missouri Division of Mental Retardation and Developmental Disabilities. (August 31, 2010). *System Transformation Initiative.* Accessed October 4, 2010. Retrieved from http://dmh.mo.gov/mrdd/transform/transformation.htm.

needs and aimed at building resiliency and facilitating recovery.[16] Titled the "Comprehensive Plan for Mental Health," this 5-year plan (2008 through 2013) was approved by the federal Substance Abuse and Mental Health Services Administration (SAMHSA) in June 2008.

In 2007, as a result of funding made possible in the 2005 Deficit Reduction Act (DRA), Missouri applied for and was awarded a $17.7 million, five-year federal "Money Follows the Person" grant to transition 250 nursing home residents to community settings and remove barriers that may prevent nursing home residents from returning to the community. The federal funds are being supplemented by $4.5 million in state dollars.17 The objectives of the demonstration were to transition a minimum of 250 elderly or disabled people who chose to move from state habilitation centers and nursing facilities into the community; eliminate barriers that prevent individuals currently residing in state institutions from accessing needed long-term community support services; improve the ability of the Missouri Medicaid program to continue provision of home and community-based long-term care services to individuals who choose to transition from institutional to community settings following the demonstration; and ensure that procedures are in place to provide continuous quality improvement in long-term care services.

Improving Access, Reducing Fragmentation

Legislation passed in 2007 noted that several Missouri agencies shared oversight responsibility for long-term care programs and services. Programs and services were organized according to diagnosis, age, type of disability, funding source, or type of service. This fragmentation makes it very difficult for persons in need of long-term care to identify what services are offered, which ones they are eligible for, what is available in their community and what they can afford. Often eligibility criteria are different, and multiple applications that ask for similar information are required.

National recognition of the problem of fragmentation has led to streamlining, simplifying and improving access to services. Improvements have been supported at the federal level by various grant programs. Many states have taken advantage of federal funds to begin the process of easing access to long-term care programs and services.

Missouri Efforts to Improve Access to Long-Term Care Services

In Missouri, Senate Bill 577 created the Missouri HealthNet Oversight Committee charged with evaluating the redesign of the Missouri Medicaid program. This same statute created the Comprehensive Entry Point Subcommittee (CEP) to make recommendations to the Missouri Department of Health and Senior Services (DHSS) on the development of a comprehensive entry point system, and to improve the availability of and access to information and services. In

16 Missouri Department of Mental Health. (2008). *Review of the State of Missouri Comprehensive Plan for Mental Health: Creating communities of Hope.* Accessed October 4, 2010. Retrieved from http://dmh.mo.gov/transformation/Review-MoCMHP-FINAL.pdf.

17 Kassner, E., et al. (July 2008). *A Balancing Act: State Long-Term Care Reform.* AARP Public Policy Institute.

its October 2008 report, the Subcommittee recommended streamlining and improving access to information and services through the legislative process.[18]

At the same time, DHSS submitted a grant application to the Administration on Aging for funding for a Person-Centered Hospital Discharge Planning/Aging and Disability Resource Center (ADRC) in Missouri. The state received a grant award of $1.6 million in September 2008.[19] The federal Centers for Medicare and Medicaid Services (CMS) and Administration on Aging (AoA) launched the ADRC grant initiative to promote the integration of long-term care information and referral services; benefits and options counseling services; access to publicly and privately financed services; and benefits for those in need of long-term supports, and their families.

A recent report on long-term care rebalancing in Missouri summarized the state's efforts to promote and improve access to long-term care services and supports:

- Significant thought and consensus building has been put into the rebalancing discussion;
- IT capacity exists to streamline and automate many functions such as intake and assessment, electronic health records (EHR), discharge planning and transitions to the community;
- A lack of global approach leads to fragmented policy and oversight, and confusion for consumers;
- A lack of consistent leadership is blamed for little or no strategic planning for long-term care;
- Seniors face barriers transitioning out of nursing facilities into the community; and
- Certificate of Need policy revisions are needed to address capacity and quality.[20]

Paying for Long-Term Care

Nationally, the sources of payment for long-term care include Medicaid (49%), Medicare (20%), self-pay (18%), private insurance (7%), and other public/private funding (5%). This does not include the cost of care provided by family and friends.[21] The following section describes the various funding mechanisms for long-term care services.

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18 Department of Health and Senior Services. (September 12, 2008). *Comprehensive Entry Point Subcommittee Report.* Accessed October 4, 2010. Retrieved from http://www.dhss.mo.gov/CEPS/Draft_9-12-2008.doc.

19 Centers for Medicare and Medicaid Services. (2008). *States Get Federal Grants To Create Increased Opportunities For Individuals To Have Person-Centered Plans For Home And Community-Based Services.* Accessed October 4, 2010. Retrieved from http://www1.cms.gov/RealChoice/Downloads/FY08RCSCgrantannouc_awardsfinal508.pdf.

20 Trail, M. and Kellenberg, R. (July 2010). *Long-Term Care Rebalancing Considerations in Missouri.* Missouri Foundation for Health.

21 US Department of Health and Human Services. (May 12, 2010). *National Clearinghouse for Long-Term Care Information.* Accessed October 4, 2010. Retrieved from http://www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx.

Medicare

Medicare pays for nursing home or home-based care only following an inpatient hospitalization of at least three days. It does not pay for nursing home care for an extended period of time. Medicare is the federal health insurance program for the disabled and adults age 65 and older.

After a patient is discharged from a hospital, Medicare coverage for nursing home care lasts up to 100 days, or until an individual's needs change from skilled care to custodial care. Some hospitals have distinct part-skilled nursing facilities. Patients may or may not be transferred to a free-standing skilled nursing facility prior to exhausting Medicare benefits. A Medicare beneficiary's average length of stay in a nursing facility is about 31 days per benefit period. A benefit period is a time frame that begins the first day a patient stays overnight in the hospital and continues until the patient has been out of the hospital for 60 consecutive days. A new benefit period begins with each hospitalization.

In addition, Medicare will pay for very limited home health care, usually associated with a recent hospitalization. Medicare will also pay for hospice services. The federal government spent roughly $42 billion on Medicare long-term care services in 2006.

Medicaid

Medicaid is a federal and state funded program for persons who meet certain income and asset criteria, or fit a defined eligibility category. The specific criteria are reflected in each state's Medicaid State Plan and must be approved by the CMS. The funding for Medicaid services is a combination of state funding matched by federal funds. The percent of federal match for each state is based on a variety of factors and is revised annually by CMS. This percent ratio is termed the Federal Medical Assistance Percentages (FMAP). Missouri's FMAP is 64.5 percent federal and 35.5 percent state.[22] In 2008, the federal government and states spent a total of $115 billion on Medicaid payments for long-term care.[23]

Medicaid Institutional Care

Medicaid has traditionally been, and continues to be, the primary payer for long-term care services. However, the services paid for by Medicaid have largely favored institutional care in nursing facilities, intermediate care facilities for the mentally retarded (ICFs/MR), and hospitals. Prior to the option to provide alternative HCBS using a Medicaid waiver, there were few alternatives to institutional care. The costs of institutional care can be much more than the costs of HCBS. In some cases, providing modest HCBS and supports make it possible for a family to continue to provide care to a loved one at home.

Medicaid Home and Community-Based Services Waivers

Medicaid HCBS waivers provide more flexibility to states and have been the major mechanism for states to fund home and community-based long-term care. Waivers are used to offer benefits that

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22 Missouri Foundation for Health. (Spring 2010). *Missouri Medicaid Basics.* Accessed October 4, 2010. Retrieved from http://www.mffh.org/mm/files/MedicaidBasics2010.pdf.

23 The Kaiser Commission on Medicaid and the Uninsured. (June 2010). *Medicaid: A Primer.* Accessed October 6, 2010. Retrieved from http://www.kff.org/medicaid/upload/7334-04.pdf.

may not normally be available, and/or provide services in a different way than the Medicaid program, or to a different population, as defined in each state's Medicaid Plan. States must submit a waiver application to the federal CMS in order to implement an HCBS waiver. Medicaid beneficiaries must meet the income and other eligibility criteria, usually a limit on assets, in order to qualify for Medicaid-funded services. Medicaid waivers are required to include a cost neutrality statement. That is, the waiver cannot cost the state or federal government more on average than services would cost if they were paid for under the "regular" Medicaid program. There are also usually enrollment caps that limit the number of participants in each waiver.

Missouri increased Medicaid funding for home- and community-based waiver services by 48.8 percent from 2004 to 2009. Expenditures for persons with developmental disabilities in intermediate care facilities (ICFs/MR) have decreased by 40 percent, at the same time expenditures for HCBS for this population have increased by 54.4 percent.

Efforts have been made to reduce the Medicaid costs of long-term care. These include using less-costly HCBS waivers, creating state long-term care insurance partnership programs, and providing tax or other incentives for individuals and employers to encourage the purchase of private long-term care insurance policies.

Home and Community-Based Services Medicaid DRA Act Options

Section 6086 of the DRA established a new optional Medicaid benefit that allowed states, through the Medicaid state plan, to cover HCBS for Medicaid beneficiaries with disabilities or chronic conditions, starting in January 2007. Prior to the enactment of DRA, states were generally required to receive an HCBS waiver to cover these services. However, this new HCBS benefit differs in several ways from the structure of current Medicaid state plan benefits and the waiver program.

For example, unlike other Medicaid state plan benefits, this benefit is limited to individuals whose income does not exceed 150 percent of the federal poverty level (FPL). Additionally, the state must establish more stringent eligibility criteria for institutional services, and permit states to cap enrollment, maintain waiting lists, and offer the option without providing services statewide.

Long-Term Care Partnership Insurance Policies

In the early 1990s, the Robert Wood Johnson Foundation funded four states (California, Connecticut, New York and Indiana) to develop a long-term care insurance partnership program. These programs were designed to test a new model of insuring long-term care services through cost-sharing incentives that encourage individuals to purchase long-term care insurance to reduce the states' Medicaid long-term care burden. Long-term care partnership policies pay for both institutional and home and community-based long-term care, with certain limitations on payment and duration of coverage.

While the partnership programs have not yet attracted the desired numbers of middle- and low-income persons, the relative savings achieved by the programs in the four demonstration states prompted Congress to lift the moratorium on states' participation to permit other states to offer partnership programs.

The Missouri Department of Insurance, Financial Institutions and Professional Registration previously launched the "Own Your Future" campaign educating the public about long-term care, encouraging the public to plan for the cost of long-term care services, and providing a Long-Term Care Partnership Program. The first policies were offered in late summer 2008.[24] The Lt. Governor's Office of Advocacy & Assistance for Seniors reports that actual purchase of the policies has lagged behind expectations.[25]

Program for All-Inclusive Care for the Elderly (PACE)

This program is a comprehensive service delivery system for the frail elderly. PACE organizations are paid a capitated rate to provide all levels of care to program participants, from services and supports to maintain independence, up to and including hospitalization. Eligibility to enroll in the PACE program includes the requirement that individuals must be 55 years of age or older, reside in the service area of the PACE organization, be determined by the Missouri Department of Health and Senior Services to need the level of care required for nursing facility services, and be recommended by the PACE staff for PACE program services as the best option for their care. Individuals may be entitled to Medicare Part A, enrolled under Medicare Part B or eligible for MO HealthNet to enroll in the PACE Program. The PACE organization provides the full range of preventive, primary, acute, and long-term care services 24 hours per day, 7 days per week to PACE participants.[26]

Other Methods of Payment

Very few private insurance policies are sold that cover either institutional or home and community-based long-term care. Few people can afford to pay for institutional or home and community-based long-term care using their income and assets (self-pay). At the same time, eligibility for publicly funded long-term care services requires individuals to "spend down" their assets and pay a share of the cost, depending on their income level, in order to qualify for Medicaid services.

Value of Informal Care

Since the vast majority of persons in need of long-term care live in their own homes or other residential settings, and most of the care is provided by family and friends, the economic value of the care provided is significant. Based on national data from 2006, the value of informal care provided by family and friends is estimated to be $375 billion.[27] As a result, public health policymakers are sensitive to the need to provide supports to informal caregivers while not replacing their role with publicly funded services. Programs to provide modest supports such as

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24 Department of Insurance, Financial Institutions and Professional Registration. (May 19, 2010). *Long-term Care Insurance.* Accessed October 4, 2010. Retrieved from http://insurance.mo.gov/consumer/LongTerm/.

25 Trail, M. and Kellenberg, R. (July 2010). *Long-Term Care Rebalancing Considerations in Missouri.* Health Management Associates for the Missouri Foundation for Health.

26 Missouri Department of Social Services. (May 11, 2009). *About the Missouri HealthNet Division: Medicaid Waivers.* Accessed October 5, 2010. Retrieved from http://www.dss.mo.gov/mhd/general/pages/about.htm.

27 AARP Public Policy Institute. (November 2008). *Valuing the Invaluable: The Economic Value of Family Caregiving 2008 Update.* Accessed on October 5, 2010. Retrieved from http://assets.aarp.org/rgcenter/il/i13_caregiving.pdf.

information on and referral to ancillary services, temporary respite, and education and counseling for family caregivers are receiving increased consideration. Providing supports for informal caregivers is important because of individual preference to be cared for at home, and because one of the most significant predictors of institutionalization is the health of the family caregiver.

Funding Long-Term Care for Persons with Developmental Disabilities

Developmental disabilities (DD) are defined in federal regulations as "…severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22."

Some states use the federal definition and others develop a state-specific definition when determining eligibility for mental retardation or developmental disabilities (MR/DD) services. Missouri uses the following state-specific definition:

> A developmental disability is a disability which is attributable to mental retardation, cerebral palsy, epilepsy, head injury, autism, or a learning disability related to a brain dysfunction, or any other physical or mental impairment which occurs before age 22. It must be determined that this disability is likely to continue indefinitely and that it results in a substantial functional limitation in two or more of the following six areas of major life activities: self care, receptive and expressive language development and use, learning, self-direction, capacity for independent living or economic self sufficiency, and mobility.

States generally spend more on HCBS and provide a wider array of community-based options for persons with DD than for other individuals in need of long-term care services and supports. Persons with DD and their advocates have worked successfully to reduce institutional service utilization and increase residential and home-based supports. Most states now fund a majority of their MR/DD services through Medicaid. Consumers and advocates have also been at the forefront of consumer directed care options and person centered planning, permitting consumers to have greater control over both planning and purchasing of services and supports. There are four Medicaid waivers to provide services and supports for Missourians with developmental disabilities.

Funding Long-Term Care for Persons with Psychiatric Disabilities

Medicaid funding for persons with psychiatric disabilities who need long-term supports and services is primarily provided to persons residing in the community, either at home or in residential settings and psychiatric hospitals. Community-based services are primarily provided by community mental health centers, Medicaid prepaid mental health plans, or Medicaid health maintenance organizations.

However, if a person is residing in a facility classified as an institution for mental disabilities (IMD), Medicaid coverage for IMD services is usually restricted to persons under age 18, or over the age of 64. This limitation is referred to as "the IMD exclusion." An IMD is a hospital, nursing facility, or other institution of more than 16 beds that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care, and related services.

Two states operate HCBS waivers for persons who have a psychiatric disability but need nursing facility services (Colorado and Wisconsin). Several states operate HCBS waivers for children with a serious emotional disturbance (SED) who would otherwise be in a psychiatric hospital. States also receive federal mental health and substance abuse block grant funding and contribute state funding to provide additional services to persons with psychiatric disabilities. Medicare provides limited mental health services, primarily outpatient services and inpatient acute hospital services subject to a lifetime maximum benefit.

Funding Long-Term Care for Persons in Jails or Prisons

The federal government will not provide a federal match for health care or long-term care provided to persons who reside in a jail or prison. Services for this population are entirely state funded. CMS has indicated that under federal law, incarceration does not affect an individual's eligibility for Medicaid, but rather the state's ability to claim federal matching funds.[28] Federal regulations do provide opportunities for federal matching funds for the cost of inpatient care in a hospital or skilled nursing facility that is not located within a correctional facility and not owned or operated by the correctional agency, where the inmates are otherwise eligible for Medicaid. In Missouri, a shift in site of care away from correctional facilities to free-standing long-term care institutions could reduce the cost of such care to the state general fund significantly. There may also be federal matching funds available for Medicaid targeted case management for persons on probation to pay for coordination of care.

Opportunities under Health Reform

The Patient Protection and Affordable Care Act (ACA) provides additional opportunities for states to expand HCBS and decrease reliance on institutional care. [29]

Medicaid Community First Choice Option

Provides enhanced federal match for states to offer certain HCBS to persons requiring an institutional level of care who have incomes below 150 percent of the FPL. (Section 2401 – effective date 10/1/2011)

HCBS through Medicaid State Plan Amendments rather than through the Waiver Process

Permits the federal Secretary of Health and Human Services to create Medicaid state plan authority instead of waivers to cover HCBS to individuals up to 300 percent of the federal benefit rate (Section 2402 – effective 2011). These requirements differ from the DRA in that they require coverage statewide and do not permit maintaining waiting lists.

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28 Streiner, R. (December 12, 1997) *Clarification of Medicaid Coverage Policy for inmates of a Public Institution.* Center for Medicare and Medicaid Services. Accessed October 5, 2010. Retrieved from http://www.colorado.gov/cs/Satellite?blobcol=urldata&blobheader=application%2Fpdf&blobkey=id&blobtable=MungoBlobs&blobwhere=1251618397983&ssbinary=true.

29 Trail, M. and Kellenberg, R. (July 2010*). Long-Term Care Rebalancing Considerations in Missouri.* Health Management Associates for the Missouri Foundation for Health.

Money Follows the Person Rebalancing Demonstration
Extends the existing demonstration grant authority to award grants to states through 2016. (Section 2403 – effective 2010)

Protection for Recipients of HCBS against Spousal Impoverishment
Requires states to adopt rules preventing spousal impoverishment under certain waivers. (Section 2404 – effective January 1, 2014)

State Aging and Disability Resource Centers (ADRCs)
Allocates $10 million annually to support ADRCs under the Older Americans Act. (Section 2405 – effective 2010 through 2014)

Community Living Assistance Services and Supports Act (CLASS)
Provides a national insurance program for purchasing community living assistance services and supports, a long-term care insurance program financed by voluntary payroll deductions. (Section 8002 – effective 2012)

Medicaid Health Home for Chronic Conditions
Creates a new Medicaid state plan option to provide health homes for beneficiaries with chronic conditions at 90 percent of FMAP during the first eight fiscal quarters the state plan amendment is in effect. This provides up to $25 million per state for a planning grant. (Section 2703 – start date January 1, 2011)

Incentives for Offering HCBS as an Alternative to Nursing Homes
Establishes a State Balancing Incentive Program to provide a temporary FMAP increase for HCBS for states that undertake structural reforms to increase diversion from institutions and expand the number of people receiving HCBS. (Section 10202 – start date October 1, 2010).

Implications

States continue to explore options to promote choice, examine how long-term care services and supports are accessed and received, and leverage the effective use of Medicaid funding. There continue to be opportunities for Missouri to build upon existing programs and initiatives. Key strategies include:

- Monitor the progress and review the evaluations of the grant programs for effectiveness in avoiding institutionalization and providing appropriate care;
- Plan for integration of models of care from the grant programs as the programs expire;
- Work within the context of the state's Olmstead Plan to explore other opportunities for expanding home- and community-based care;
- Review the 2008 Comprehensive Entry Point report recommendations for options to streamline and improve access to long-term care information and services;
- Evaluate existing HCBS programs and new opportunities such as the DRA HCBS state plan option, as well as the coverage gaps and costs of existing programs;

- Evaluate opportunities and costs of integrating financing for acute and long-term care;
- Examine opportunities to provide modest supports to family caregivers to permit care recipients to remain at home or in the community; and
- Identify opportunities to claim federal matching funds for Medicaid-eligible inmates who are in need of inpatient long-term care services in a skilled nursing facility, or for targeted case management for persons on probation.

Additional recommendations were offered by a recent report on long-term care rebalancing:

- Develop a state profile for assessing the long-term care programs based on the CMS profile template (technical assistance tool developed by CMS);
- Develop a comprehensive long-term care supports and services quality strategy to provide the framework for evaluating fiscal and administrative impacts of long-term care program policies;
- Leverage technology already in place;
- Reform the certificate of need to ensure appropriate access to services is maintained;
- Create a nursing home case mix reimbursement methodology to incentivize care for the highest need residents in facilities; and
- Explore alternative delivery system design(s).[30]

30 Trail, M. and Kellenberg, R. (July 2010). *Long-Term Care Rebalancing Considerations in Missouri.* Health Management Associates for the Missouri Foundation for Health.