

Issues in Missouri Health Care 2009

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

Acknowledgement

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Issue Statement

One of the driving forces behind the projected increased demand for long-term care services over the next 20 years is the aging of Baby Boomers.¹ It is estimated that by 2010, 14.9 percent of Missouri's population will be 65 years of age or older. By the year 2020, Missourians aged 65 and over are projected to be 18.2 percent of the population.²

Most individuals want to receive long-term care services in their own home or in a community-based residential setting. 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 (February, 2000) 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? Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks, 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. Persons in need of long-term care include elders, persons with physical, developmental, or mental disabilities.⁴ Table 1 below reflects the numbers of Missourians with disabilities.

Table 1: Missouri Disability Statistics

	Number/Percent of Missourians	
Persons with a Disability	937,000	17.9%
Persons with a Disability having difficulty with self-care	166,000	3.2%

Source: "Missouri Disability Statistics from 2005 American Community Survey:"
Center for Personal Assistance. 2005. Accessed 9 September 2008.

¹ Baby boomer describes a person born between 1946 and 1964.

² "Missouri State Plan on Aging" *Division of Senior and Disability Services*. 27 September 2007 , pg 4

³ Fradkin, L.G and A Heath. *Caregiving of Older Adults*. Santa Barbara: ABC:CLIO, Inc., 1992.

⁴ "Fact Sheet: Selected Long-Term Care Statistics." *Family Caregiver Alliance*. 2005. Accessed September 2008. (http://caregiver.org/caregiver/jsp/print_friendly.jsp?nodeid=440)

Who Provides Long-term Care and Where is it Provided? It is estimated that 79 percent of all people who need long-term care live at home or in community residential settings rather than in institutions.⁵ 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 8 percent receive all of their care from a formal caregiver.⁶ Table 2 below shows the ages and living circumstances of Missourians with disabilities.

Table 2: Characteristics of Missourians with Disabilities Having Difficulty with Self-Care

Characteristics of Missourians with Disabilities	
Age	Number
5-17	9,000
18-64	90,000
65 and older	67,000
Place of Residence	
Living alone	39,000
Living with others	127,000

Source: "Missouri Disability Statistics from 2005 American Community Survey:"
Center for Personal Assistance. 2005. Accessed 9 September 2008.
 (http://www.pascenter.org/state_based_stats/state_statistics_2005.php?state=missouri)

Promoting Choice, Providing Options

While the overwhelming majority of people would prefer to stay in their own homes when and if they need long-term care services, the type and availability of long-term care is largely a reflection of the programs and services for which the federal government will 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.

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 toward home and community-based care. Home

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

- *Six in ten Missourians are worried about not having enough choices among long-term care services.*
- *Eighty-five percent of Missouri AARP members would prefer to receive long-term care in their own homes or in a home-like setting. Only 3 percent want to go to nursing homes.*
- *More than half of Missouri members said that they 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 their own homes and communities.*

Source: AARP. "2005 Missouri Member Survey on Long-term Care, Assisted Living and Medicaid." Washington DC: Knowledge Management (February 2006).

⁵ Ibid.

⁶ "NFCSP Complete Resource Guide" *Administration on Aging*. 9 September 2004. Accessed September 2008. (http://www.aoa.gov/prof/aoaprof/caregiver/careprof/progguidance/resources/nfcsp_resources_guide.aspx)

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 is “rebalancing.” (See page 8 for a list of Missouri’s waivers.)

Missouri was an early investor in attempting to reform the long-term care system and provide choice to care recipients.⁷ *Missouri Care Options* reform initiatives implemented in 1992 were focused on shifting the focus 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 adequate quality of care and quality of life.

The table 3 illustrates the progress made rebalancing long-term care for elders:

Table 3: Medicaid Expenditures for Long-Term Care

Type of Service	Medicaid Participants			Expenditures (millions)		
	1999	2004	Change	2001	2006	Change
HCBS	57,407	73,160	+15,753	\$228	\$320	+\$92
Nursing Homes	39,762	39,606	-156	\$726*	\$763	+\$37

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

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

- In 1999, the U. S. Supreme Court issued an interpretation of 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 the President’s order of June 2001 directing federal agencies to assist states in developing plans to comply with the Court’s decision, Missouri developed Olmstead Plan under the auspices of the Governor’s Council on Disabilities.⁸
- In 2005, the Missouri Department of Mental Health received a \$2.97 million, 5-year federal Medicaid System Transformation Grant which was made possible by the federal “New Freedom Initiative” unveiled by President George W. Bush in 2001. This grant is designed to support persons with developmental disabilities who have long-term care needs through promoting community living.⁹ Missouri has developed

⁷ "Missouri State Plan on Aging" *Division of Senior and Disability Services*. 27 September 2007

⁸ “The 1999 *Olmstead* Supreme Court Decision and Missouri” *Center for Personal Assistance*. October 2006. Accessed 9 September 2008.

(http://www.pascenter.org/state_based_stats/olmstead_home.php?title=Olmstead%20Plans%20and%20Lawsuits&state=missouri)

⁹ “Systems Transformation Initiative Overview.” *Missouri Division of Mental Retardation and Developmental Disabilities*. Accessed 9/9/2008

([http://www.dmh.missouri.gov/mrdd/transform/Grant%20Overview%20\(2\).doc](http://www.dmh.missouri.gov/mrdd/transform/Grant%20Overview%20(2).doc))

a Comprehensive Plan for Mental Health that was approved by the federal Substance Abuse and Mental Health Services Administration (SAMHSA) in June 2008.¹⁰

- 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 to remove barriers that may prevent nursing home residents from returning to the community.¹¹ The federal funds are being supplemented by \$4.5 million in state dollars.¹²

Improving Access, Reducing Fragmentation

The oversight responsibility for long-term care programs and services is shared by several different Missouri state agencies. Historically, programs and services have been 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.

There has been national recognition that changes are necessary in the way long-term care services are accessed. Streamlining, simplifying and improving access to services has been encouraged 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.

What is Missouri Doing to Improve Access to Long-Term Care Services? In Missouri, Senate Bill 577 (2007) created the Missouri HealthNet Oversight Committee. The Oversight Committee has been charged with evaluating the redesign of the Missouri Medicaid Program. This same statute created the CEP. The purpose of this subcommittee is to make recommendations to the Department of Health and Senior Services (DSS) on the development of a comprehensive entry point system and to

¹⁰ *State of Missouri Comprehensive Plan for Mental Health; Creating Communities of Hope, January 2008-January 2013*, March 2008. Accessed 10/7/08 at <http://www.dmh.missouri.gov/transformation/FINALVERSIONJULY12008.pdf>.

¹¹ Kassner, Enid et al. "A Balancing Act: State Long-Term Care Reform." *AARP Public Policy Institute*. Washington DC: AARP (July 2008)

¹² The objectives of the demonstration are to: transition a minimum of 250 individuals who have disabilities and those who are aging who choose to move to the community from state Habilitation Centers and Nursing Facilities to 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 this demonstration; and ensure that procedures are in place to provide for continuous quality improvement in long-term care services.

improve the availability and access to information and services.¹³ The Subcommittee's report is due in October, 2008.

At the same time that the Subcommittee has been at work on its charge, DSS 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 grant was awarded in September, 2008.¹⁴ 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, and access to publicly and privately financed services and benefits for those in need of long-term supports and their families.

Paying for Long-Term Care

Other than the care provided informally by family and friends, the majority of long-term care is funded by Medicaid. Recent initiatives to reduce or shift the cost of long-term care from Medicaid includes using HCBS waivers, creating state long-term care partnership programs, and providing tax or other incentives for individuals and employers to encourage the purchase of private long-term care insurance policies. Following is an overview of the various current funding mechanisms for long term care services.

Medicare: Medicare does not pay for nursing home care for an extended period of time. Medicare is a federal health insurance program for disabled adults and adults age 65 and older. Medicare requires a 3-day hospital stay prior to transfer to a nursing home and after admission to the nursing facility, services provided in the nursing home must relate to the illness or injury that cause the hospitalization. After admission, Medicare coverage for nursing home care ends once an individual's needs change from skilled care to custodial care. Finally, Medicare coverage is limited to 100 days of care per benefit period. A Medicare beneficiary's average length of stay in a nursing facility is about 31 days per benefit period.¹⁵ The federal government spent roughly \$41 billion on long term care services in 2006.¹⁶

¹³ SB 577 defines a comprehensive entry point system as one that "(1) Offer(s) Missourians an array of choices including community-based, in-home, residential and institutional services; (2) Provide(s) information and assistance about the array of long-term care services to Missourians; (3) Create(s) a delivery system this is easy to understand and access through multiple points, which shall include but shall not be limited to providers of services; (4) Create(s) a delivery system that is efficient, reduces duplication, and streamlines access to multiple funding sources and programs; (5) Strengthen(s) the long-term care quality assurance and quality improvement system; (6) Establish(es) a long-term care system that seeks to achieve timely access to and payment for care, foster(s) quality and excellence in service delivery, and promote(s) innovative and cost-effective strategies; and (7) Stud(ies) one-stop shopping for seniors as established in section 208.612."

¹⁴ Department of Health and Senior Services. "Comprehensive Entry Point System Subcommittee" Accessed 9 September 2008. (<http://www.dhss.mo.gov/CEPS/>)

¹⁵ "Own Your Future." *Own Your Future*. Accessed 8 September 2008 (<http://www.ownyourfuture.mo.gov/>)

¹⁶ Medicare Spending and Financing Fact Sheet, Kaiser Commission on Medicaid and the Uninsured, September 2008. Accessed 10/08 at http://www.kff.org/medicare/upload/7305_03.pdf.

Medicaid: Medicaid is a federal and state funded program for persons who meet certain income and asset criteria. 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 federal funding matched by state funds. The percent of state match for each state is determined by statute based on a variety of factors and is revised annually. In 2004, the federal government spent approximately \$61 billion on long term care services while states spent nearly \$40 billion.¹⁷

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 home and community-based services using a Medicaid waiver, there were few alternatives to institutional care.

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. States must submit a waiver application to the federal CMS in order to implement a 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.

HCBS Medicaid DRA Options: Section 6086 of the DRA established a new optional Medicaid benefit that allows 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 a HCBS waiver to cover these services. However, this new HCBS benefit differs in several ways from the structure of both 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. Additionally, the state must establish more stringent eligibility criteria for institutional services and permits states to cap enrollment, maintain waiting lists and offer the option without providing services statewide.

Only one state (Iowa) reported having taken advantage of the HCBS State Plan option in FY 2007. One state (Colorado) reported implementing this DRA option in FY 2008 and three additional states reported plans to implement the HCBS State Plan option in FY 2009 (Connecticut, Nevada and Texas).¹⁸

Long-term Care Partnership Insurance Policies: In the early 1990s, Robert Wood Johnson Foundation funded a demonstration project in four states (California,

¹⁷ Medicaid Facts: Federal and State Share of Medicaid Expenditures, FFY 2004, Kaiser Commission on Medicaid and the Uninsured. Accessed 10/08 at <http://www.kff.org/medicaid/upload/kcmu032106table1.pdf>.

¹⁸ Smith, Vern et al. *Headed for a Crunch: An Update on Medicaid Spending, Coverage and Policy Heading into an Economic Downturn Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2008 and 2009.* (September 2008).

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 to 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 as part of the DRA.¹⁹ Thirteen states reported having Long-Term Care Partnership Programs in state fiscal year (SFY) 2007; eight states reported implementing a program in SFY 2008 and seventeen states indicated that they were planning to implement a program in SFY 2009, which would bring the total to three-fourths of all states.²⁰

The Missouri Department of Insurance, Financial Institutions and Professional Registration (DIFP) has launched the "Own Your Future" campaign to educate 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 will be offered in late summer 2008.²¹ Table 4 below identifies Missouri's existing home and community-based long term care waivers.

Table 4: Missouri Medicaid Long-Term Care Waivers

Waiver	Eligibility	Number of Clients	Expenditures
Aged and Disabled	Age 63+, meet NH level of care	23,330	\$82,133,150
AIDS Waiver	AIDS/HIV diagnosis	76	\$1,185,980
Independent Living	Age 18-64, Physical or cognitive disability, NH LOC	509	\$2,017,766
Lopez Waiver	Age 0-18, total developmental disability	188	\$1,679,401
MR/DD Comprehensive	Developmental Disability requiring care in an ICF/MR	7570	\$275,881,503
MR/DD Community Support Waiver	Developmental Disability requiring care in an ICF/MR	475	\$1,567,453
Physical Disability Waiver	Age 21+, Physical Disability	26	\$2,122,059

¹⁹ Dalton, Ryan et al. *Task Force Report: Missouri's Long-Term Care Partnership Program*. St. Louis: Brown School of Social Work (2007)

²⁰ Smith, Vern et al. *Headed for a Crunch: An Update on Medicaid Spending, Coverage and Policy Heading into an Economic Downturn Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2008 and 2009*. (September 2008).

²¹ "Own Your Future." *Own Your Future*. Accessed 8 September 2008 (<http://www.ownyourfuture.mo.gov/>)

Source: "Missouri Disability Statistics from 2005 American Community Survey:" *Center for Personal Assistance*. 2005. Accessed 9 September 2008 (http://www.pascenter.org/state_based_stats/state_statistics_2005.php?state=missouri). And "Missouri's Guide to Home and Community Based Services" *Division of Medical Services*. Missouri: Department of Social Services (15 March 2007)

Other Methods of Payment: Very few private insurance policies are sold that cover either institutional or home and community-based long-term care. Very few people can afford to pay for institutional or home and community-based long-term care using their income and assets (out-of-pocket). At the same time, eligibility for publicly funded long-term care services requires individuals to "spend down" their assets and pay a share of 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 \$350 billion.²² As a result, public health policy makers are increasingly sensitive to the impact of changes to programs and services in terms of the potential additional burden for informal caregivers. Programs to provide modest supports such as information on and referral to available services, temporary respite, education and counseling for family caregivers are receiving increased consideration. Providing supports for informal caregivers is important because of the preference to be cared for at home and because one of the most significant predictors of institutionalization is the health of the family caregiver.²³

Funding Long-term Care for Persons with Developmental Disabilities: Developmental disabilities (DD) are defined in federal rule as severe, life-long disabilities attributable to mental and/or physical impairments, manifested before age 22. Developmental disabilities result in substantial limitations in three or more areas of major life activities:

- capacity for independent living
- economic self-sufficiency
- learning
- mobility
- receptive and expressive language
- self-care
- self-direction

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 a state-specific definition:

²² "Valuing the Invaluable: 2006 Economic Value of Family Caregiving Is \$350 Billion," AARP, June 22, 2007. Accessed 10/08 at http://www.aarp.org/family/caregiving/articles/valuing_the_invaluable.html

²³ Kennedy, J. and Walls, C. *A National Profile of intra-household ADL/IADL assistants: Population estimates from the 1992 and 1993 Surveys of Income and Program Participation*. Champaign: Department of Community Health, University of Illinois at Urbana (1997).

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 mental or 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.[Missouri Department of Mental Health.]

States generally spend far more on HCBS for persons with DD, and provide a wider array of community-based options, than for other groups of persons needing long-term care services. Persons with DD and their advocates have worked successfully to reduce institutional service utilization and to increase both residential and home-based supports. Most states now fund a majority of their MR/DD services through Medicaid, retaining a relatively small amount to provide services to persons who are not Medicaid eligible or to cover services or supports not covered by 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.

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 both at home or in residential settings and in psychiatric hospitals. Community-based services are primarily provided by community mental health centers and Medicaid prepaid mental health plans or Medicaid health maintenance organizations (HMO).

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 who 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 payment for health care or long-term care for persons in a jail or prison. Funding for services for this population is 100 percent state funds.

Implications

States continue to explore options to provide choice in how long-term care services and supports are accessed and received, and to leverage the effective use of Medicaid funding. There continue to be opportunities to build upon existing programs and initiatives.

- 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 grant programs expire.
- Work within the context of the state's Olmstead Plan to explore other opportunities for expanding home and community-based care.
- Review upcoming CEP report recommendations for an analysis of best practices and policy options for improving access to long-term care 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.