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Community Integration for People with Disabilities: The Role of Long-Term Care and the Medicaid Buy-In

The purpose of this brief is to provide persons working in Medicaid or disability employment with an understanding of some of the essential components of Medicaid long-term care programs. It is also intended to show examples of how some states have incorporated aspects of long-term care services and supports (LTSS) into their Medicaid Buy-In (MBI) programs. An understanding of the components of long-term care can be useful in identifying services and supports that may be valuable to persons in MBI programs as well as being useful in future planning for the sustainability of the MBI program as a potential part of a long-term care system. Understanding long-term care is important because “long-term care provided outside of institutions...enables many persons with disabilities to maintain their independence; avoid institutionalization; and participate in family, community, and economic activities.”¹

There are multiple definitions of long-term care (LTC), but most definitions agree that long-term care:

- Focuses on both medical and social services;
- Addresses chronic care needs; and
- Can be provided in a multitude of settings.

¹ Ng, T, Harrington, C, Kitchener, M, “Long-Term Care: Who Gets It, Who Provides It, Who Pays, and How Much?” *Health Affairs*, 2010:29, pg 11.



The Assistant Secretary for Planning and Evaluation of the Department of Health and Human Services defines long-term care as a:

“Range of medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short- or long term and may be provided in a person’s home, in the community, or in residential facilities (e.g., nursing homes or assisted living facilities).”²

Paying for Long-Term Care

Medicaid is the primary payer for nursing home care in the United States today. Medicare plays a much smaller role than Medicaid, and does not finance comprehensive long-term care. However, Medicare does provide significant funding for the first several months of nursing home care, primarily focusing on medical stabilization and rehabilitation services. Additionally, many individuals pay for nursing home costs out-of-pocket at the time of initial placement; as time goes on, people often spend enough of their private resources to become eligible for Medicaid.

Medicaid is also the primary payer for home and community-based care through waivers and state plan option services. Medicare provides very few services and supports in the home or community. Medicare does pay for home health services, usually on a time-limited basis, and only for persons who are home bound. Medicare also pays for some durable medical equipment, such as motorized wheelchairs, that can support seniors and individuals with disabilities living at home.

Range of Services

Medicaid long-term care services usually include nursing home care, home and community-based services, and personal assistance services. Nursing home care is a mandatory Medicaid service. Therefore, a state that participates in Medicaid must make nursing home care available to all persons eligible for Medicaid. In contrast, home and community-based programs are optional services that a state can choose whether or not to include in Medicaid. The primary administrative vehicle for states to provide home and community-based services is through Medicaid waivers. Waiver programs often include some type of residential model or models such as assisted living, residential care facilities, or adult foster care. These models provide for a place to live as

² Assistant Secretary for Planning and Evaluation, HHS website: <http://aspe.hhs.gov/daltcp/diction.shtml#LTC>



well as personal assistance services (PAS) and other long-term care supports. Waivers can also provide services in a person's private residence. Personal assistance services can also be provided through a Medicaid State Plan option.

When looking at the range of services in another state, it is important to understand how the state is defining the service. A state may use the same language for a service that another state uses but the care provided is not the same. For example, terms such as personal care, adult care homes, board and care, residential care, and assisted living are used in many states, but what constitutes these services are often quite different from state to state. It is a good idea to understand whether service definitions are comparable when analyzing long-term supports in multiple states. Many states have their statutes and administrative rules online and define these services in these documents.

Administration

It is important to understand how the long-term care system is administratively structured in a state. The administrative design of the system includes who has budget authority for programs, how LTC services are delivered, where policy decisions are made, where important data is kept, and how training for programs is developed and delivered. The structure of these programs has significant implications regarding the care that is provided, and varies from state to state. Some states have consolidated long-term care programs into a single agency. Other states have these programs administered in different agencies based on funding sources and/or different populations. For example, long-term services and supports for the elderly may be administered in one agency, services for persons with physical disabilities may be administered in a different agency, and persons with developmental disabilities may be served in another agency.

When comparing long-term care systems across states, it usually more helpful to make the comparison between states with similar administrative structures. States with highly integrated long-term care systems may not find meaningful comparisons with states that are decentralized in design.

Eligibility for Long-Term Care Services and Supports

Eligibility for Medicaid long-term care services and supports is a two step process. To be eligible, a person must first meet financial eligibility requirements, including income and asset limits, and then must also have a functional impairment level that requires the long-term services and supports. States have some flexibility when establishing the income and asset thresholds for long-term care. They also have flexibility to define the level of impairment required for the services and supports.



To be eligible to receive LTSS through a waiver, a person must meet the level of care criteria to be in a nursing home. This level of care is established by the state and uses a medical and social assessment, often called a functional assessment, to measure the person's ability to perform certain Activities of Daily Living (ADLs). ADLs usually include:

- bathing;
- dressing;
- grooming;
- eating;
- toileting; and
- mobility.

The assessment often also measures a person's cognitive ability. States sometimes also measure the person's capacity to perform Instrumental Activities of Daily Living (IADLs). IADLs differ from ADLs, and include activities such as:

- shopping;
- light housekeeping;
- money management; and
- medication management.

Some states have established a high threshold for waiver eligibility such as requiring a person to be dependent in four or more ADLs; other states may only require a dependency in two ADLs.

It is important to know what agency is responsible for administering these eligibility processes. The financial eligibility may be performed in one agency and the functional assessment for waiver eligibility may be performed in another agency. Having knowledge of the specific financial and level of care criteria is also important, as these services may provide supports to persons in the Medicaid Buy-in program if they meet the eligibility criteria.

It is also helpful to understand how long-term services and supports are delivered at the local level. This is particularly important for staff that provide training on aspects of the Medicaid Buy-in and other employment supports to the staff that does LTSS eligibility. Most states rely on staff at the county or city level to perform the eligibility and case management functions. These functions may be performed by state employees housed at the local level, or may be contracted out to local governments, or in some instances, to private, nonprofit entities. Regardless of who performs the eligibility functions, the state Medicaid agency is ultimately responsible for assuring that all facets of Medicaid eligibility are determined correctly.



Functional Assessment for Long-Term Care Services and Supports

States use a variety of assessment tools to determine the nursing home level of care, as well as to determine the kinds of LTSS a person might need. States also use different types of staff to complete the assessment. Some states use a case manager, others use a social worker, and other states sometimes use a registered nurse; depending on the situation, a state could use any or all of those disciplines to complete the assessment. The assessment usually involves a face-to-face interview with the applicant, as well as a review of relevant medical information. Many states have developed computer programs that analyze the data for the assessment tool and develop service plans indicating the type and amount of service or services a person might need, as well as the cost of the services. The federal government requires that all service plans be reviewed at least yearly but states can establish a more frequent review schedule if it is deemed necessary.

While the assessment tools used by most states often provide a comprehensive view of the person's ability to function in the community, these tools rarely assess the person's ability to work and what services might be helpful in finding and maintaining employment. However, these assessments can provide a valuable picture of the person's strengths and weaknesses for integration into the community. It can be useful for disability employment staff, Buy-in staff, and Medicaid Infrastructure Grant staff to review what is contained in these assessment tools. Examples are often on the website of the agency or agencies that perform the assessments.

Rebalancing Long-Term Care Systems

Since the inception of the home and community-based waiver program in 1981, the transition from institutional care to community-based care has focused on providing a "less restrictive" environment in which to live. The focus on deinstitutionalization was heightened in 1999, when the Supreme Court issued its Olmstead decision. In the Olmstead decision, the Court ruled that persons with disabilities, when feasible, should reside in community-based settings rather than institutions. The Court also recognized that a way to address the barriers to individuals residing in the community was for states to develop comprehensive plans for placing persons with disabilities in less restrictive living situations than institutions. As a result of the Olmstead decision, states have been involved in putting together plans to address barriers to individuals residing in the community rather than institutions.

The experiences of states in developing home and community-based services as an alternative to nursing home care has led the federal government to initiate a series of projects designed to better understand what it takes to bring



long-term care systems more into balance between these two delivery mechanisms. In 2003, Congress directed the Centers for Medicare and Medicaid Services (CMS) to commission a study that explored the various management techniques and programmatic features that states have used to rebalance their Medicaid long-term care systems, as well as state investments in long-term support services towards community care. Rebalancing was defined as reaching more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (i.e. Nursing Facilities and Intermediate Care Facilities for the Mentally Retarded) and those used for community-based supports under its state plan and waiver options. Additionally, a balanced long-term care system would offer individuals a reasonable array and adequate choice of both community and institutional options.³

The results of the CMS commissioned study on rebalancing LTC can be found at: http://www.sph.umn.edu/hpm/ltreresourcecenter/research/rebalancing/Rebalancing_state_ltc_systems.htm.

CMS also initiated the Money Follows the Person (MFP) Rebalancing Demonstration as part of a comprehensive, coordinated strategy to assist states, in collaboration with stakeholders, to make widespread changes to their long-term care support systems. This initiative provides additional federal funding to assist states in their efforts to reduce their reliance on institutional care while developing community-based long-term care opportunities enabling older persons and people with disabilities to fully participate in their communities. In 2007, CMS awarded MFP grants to 30 states and the District of Columbia; currently 29 states and D.C. are implementing MFP projects.

Long-Term Care and the Medicaid Buy-In Program

As states move to rebalance their long-term care systems, the primary emphasis has been on developing alternative housing resources in the community to meet the needs of persons who are either in nursing homes or who are at risk of needing nursing home placement. The goal is to provide living arrangements that include the necessary services and supports to assist an individual to meet the basic activities of daily living.

Addressing these issues is critical to helping people with disabilities, regardless of age, to be able to function in the community and lead more independent lives. For some persons with disabilities, however, community integration includes more complex life activities such as employment and the enhanced social interaction that comes from being employed. For individuals

³ CMS website, Rebalancing Long-Term Care, http://www.cms.gov/CommunityServices/15_Balancing.asp



that require long-term services and supports, but who are also employed or interested in becoming employed, states can use the Medicaid Buy-in⁴ to continue providing these necessary medical services while simultaneously enabling the individual to participate in the workforce.

Employment provides individuals with the opportunity to interact with more people, to be productive, and to increase earned income. All of these opportunities will assist individuals increase their independence. The design of comprehensive health care delivery systems are moving from a focus on acute and primary care to including services that address issues presented by chronic conditions. It is primarily these chronic conditions that hamper a person's ability to participate in the community by limiting their ability to perform the essential activities of daily living. Therefore, it is important to consider how services and supports can be organized in a manner that provides needed LTSS without preventing individuals from becoming or remaining employed. The Buy-in can therefore be an important tool to assist with the community integration of individuals that need LTSS.

Integrating Employment into Long-Term Care Programs—State Examples

Development of a Comprehensive Long-Term Care Assessment Tool in Minnesota

Minnesota is developing a set of standards and protocols to assess the functional needs of persons with disabilities for LTSS. Included in this initiative is development of a comprehensive assessment tool called COMPASS. The state has found that the current systems used to measure the need for LTSS are fragmented and duplicative. Additionally, current assessment tools do not reflect the complexity that disabilities and chronic conditions often present. COMPASS will focus on the specific services and supports a person needs rather than on a particular funding source. COMPASS will also more accurately reflect an individual's needs as well as the strengths and weaknesses of their current support systems. This new assessment tool will use a person-centered approach to needs determination and planning and will be Web-based.

The weight given to employment as a critical life domain is seen in the initial portion of the assessment (to be used with most persons under the age of 65). The probes that are used to understand how a person views work not

⁴ The Medicaid Buy-in program, authorized by both the Balanced Budget Act of 1997 and the Ticket to Work and Work Incentives Improvement Act of 1999, provides states with the option to expand Medicaid coverage to working persons with disabilities whose income and assets would otherwise make them ineligible for coverage.



only include questions about specific work history, but how work may have had a positive influence in their lives, how work has influenced their independence, the most important things about going to work, and the easiest and hardest things about going to work. In this initial part of the assessment, even children ages 8 through 12 will be asked questions designed to get them thinking about work and their future.

After this initial assessment is completed, there is a specific module that addresses employment in greater detail. This module must be completed on any person with a disability ages 13 to 65. It will document specific work-related issues such as barriers to employment, work modification and accommodation needs, health status, and access to necessary supports such as PAS, housing, social supports, and transportation. The module will also include a comprehensive list of resources that could address some of the barriers identified in the assessment.

The 2009 Minnesota Legislature approved funding for the Minnesota Department of Human Services, Continuing Care Administration to implement the Minnesota COMPASS beginning January 2011. The most current version of COMPASS can be found at: <http://www.hcbsstrategies.com/project%20page%20MN%20Comp%20Assessment%202nd%20pg.html>.

Comprehensive Planning to Rebalance the Long-Term Care System

New Jersey has taken a comprehensive approach to rebalancing its LTC system. Key goals of the state's rebalancing efforts are:

- Expenditures on home and community-based care should be at least equal to those for nursing home or other out-of-home expenditures;
- The state should be able to use federal resources to balance expenditures on LTC; and
- Services should involve consumer choice and control and be cost effective.

New Jersey emphasized the importance of collaboration between four state agencies to achieve its goals. These agencies included the Divisions of Disability Services, Developmental Disabilities, Medical Assistance and Health Services in the Department of Human Services and the Division of Aging and Community Services in the Department of Health and Senior Services. The state applied for and was awarded a series of federal and foundation grants to support its rebalancing plan. These grants included:

- Nursing Home Transition;
- Real Choice Systems Change;
- Nursing Home Diversion;



- Cash and Counseling;
- System Transformation;
- Money Follows the Person;
- Nurse Delegation Pilot Program;
- Aging and Disability Resource Centers (ADRC);
- Veteran-Directed Home and Community Services; and
- Medicaid Infrastructure Grant.

The New Jersey Legislature passed legislation to support rebalancing the LTC system via the Independence, Dignity and Choice in Long-Term Care Act (June 2006). The Act created a Medical LTC Funding Advisory Council that was modeled on the ADRC pilots in New Jersey. It also directed the State agencies and the State Treasurer to implement a process whereby increases in funding are allocated to home and community-based services. The legislation also developed a program called Global Options to rebalance funding and offer greater choice and control to consumers of LTC. The Global Options Waiver assists in transitions from nursing facilities to the community.

The state's various programs are intended to work together to support community integration. Individuals in nursing facilities are assisted in transitioning into community settings. Medicaid waiver programs continue necessary care services in the community. Money Follows the Person allows funds that would have been spent on nursing facility care to be used for community care with an enhanced federal Medicaid match rate. The Aging and Disability Resource Centers divert people from entering nursing facilities by providing information and referrals to community-based alternatives. Personal care services are provided by agencies, or individuals may make use of a consumer-directed model of care. If a person needs skilled nursing care, it can be provided by the Nurse Delegation Pilot. A person with a disability who wants to work and still maintain Medicaid coverage can do so through the state's Medicaid Buy-in program, NJ WorkAbility. This comprehensive approach involves coordination across multiple agencies, but provides individuals with options for a range of supports and services in different settings.

Addressing PAS Issues by Using the Deficit Reduction Act of 2005 in Kansas

The Deficit Reduction Act of 2005 (DRA) provided states with the opportunity to restructure aspects of their Medicaid program and to integrate parts of their LTSS system into a more comprehensive delivery system. In March 2006, CMS sent a letter to State Medicaid Directors providing guidance on the DRA:



“This letter...provides guidance on the implementation of the Deficit Reduction Act of 2005, Public Law Number 109-171. Section 6044, State Flexibility in Benefit Packages, adds a new section 1937 to the Social Security Act (the Act). Under section 1937, States have the option to amend their State plan to provide alternative benefit packages to beneficiaries, without regard to comparability, state wideness, freedom of choice, or certain other traditional Medicaid requirements.” See <http://www.cms.hhs.gov/smdl/downloads/SMD06008.pdf>.

Kansas took advantage of this opportunity to enhance its Medicaid Buy-in program by using provisions in the DRA. Kansas, in effect, synthesized its current Medicaid Buy-in program, the Working Healthy program, with a new benefit package called WORK that increased access to services that could be beneficial for those persons with disabilities who are working. Under Kansas’ existing Home and Community-based waivers, it was not feasible to provide Medicaid PAS to persons in their Buy-in. However, the DRA provided Kansas with the opportunity to craft a new benefit package that included PAS for individuals in the Medicaid Buy-in who needed this service.

To be eligible for this new benefit package, a person must be eligible for the Physical Disability, Developmental Disability, or Traumatic Brain Injury waivers, must be on a waiting list for those waivers, or must meet the same level of care requirements that the waivers entail. Individuals must also be competitively employed in an integrated setting and not residing in a home or property owned, operated, or controlled by a provider of services, unless that provider is a relative. Besides PAS, the new services available for Working Healthy recipients through WORK include an assessment to determine their need for PAS, Assistive Technology services not covered under the Kansas Medicaid State Plan, and Independent Living Counseling. Benefits and Work Incentives counseling is also available to Working Healthy recipients.

Texas Money Follows the Person Behavioral Health Pilot

Texas has initiated a Behavioral Health Pilot funded by a Money Follows the Person demonstration grant that focuses on providing specialized behavioral health services to help individuals with severe mental illness and/or substance use disorders transition from nursing facilities into the community. The Pilot involves the collaboration and coordination of three state agencies:

- The Department of State Health Services, which provides the specialized behavioral health services;
- The Department of Aging and Disability Services, which provides relocation and eligibility verification services; and



- The Health and Human Services Commission, which provides acute and long-term care services through Medicaid HMOs.

Potential candidates for the Pilot are identified in nursing facilities and an assessment is completed to determine their interest in residing in the community. A determination is made regarding the resources that would be needed in the community, as well as potential barriers that may prevent a successful transition. If the assessment indicates a resident could benefit from the Pilot services, they are eligible for up to six months of services while in the nursing home, and 12 months of services after relocating to the community.

Pilot behavioral health services include substance abuse treatment and Cognitive Adaptation Training (CAT), a service designed to help individuals establish daily routines, organize their environment, and build social skills. Substance abuse services include intensive individual counseling, group therapy, peer support programs, and linkages to other community supports such as Alcoholics Anonymous and Narcotics Anonymous.

Significant supportive services at the local level include:

- Assisting the individual locate and establish a residence in the community;
- Securing viable transportation services; and
- Helping the person find and maintain employment as well as essential mental and physical health services.

Community relocation assistance and advocacy are provided by Relocation Specialists from Independent Living Centers. Specialized mental health and substance abuse services are provided by the local Mental Health Authority. Health and long-term services and supports are provided by local Medicaid HMOs.

There have been some significant results from this innovative Pilot program. From April 2008 through January 2010, the Pilot provided CAT and substance abuse services to 50 participants; 88 percent of those individuals have successfully maintained independence in the community. Examples of how participants are increasing their independence include:

- Learning to operate a vehicle in order to independently commute;
- Obtaining paid employment;
- Volunteering at the nursing facility where the participant formerly resided;
- Obtaining a GED; and
- Working towards a college degree.

Participants who have completed their 365 days of services are assessed to determine whether their ability to function in the community has improved. Texas uses the Multnomah Community Ability Scale to measure an individual's



Adjustment to Living/Adaptation. Results have shown a statistically significant improvement in the areas of independence in daily life, money management, and coping abilities. Preliminary cost analysis for the Pilot indicate the overall Medicaid costs for participants during the first six months of living in the community were lower than the last six months of nursing facility placement.

Future Directions

With the recent passage of national health reform legislation in 2010 through the *Patient Protection and Affordable Care Act (P.L. 111-148)* and the *Health Care and Education Reconciliation Act (P.L. 111-152)*, Medicaid will continue to provide a significant portion of health care coverage to a broad range of individuals across the United States. According to the Congressional Budget Office, under the provisions of health reform, approximately 16 million additional individuals will receive coverage through either Medicaid or CHIP.⁵ As of the writing of this brief, many of the technical details regarding the scope of services that are likely to be included within the Medicaid expansion are awaiting regulation and policy clarifications from the Department of Health and Human Services.⁶ As such, detailed information about the services for newly eligible individuals will not be available until the regulations are promulgated.

Although health reform focuses primarily on increasing access to acute care, the legislation also includes a number of significant changes to home and community-based services in Medicaid, as well as the establishment of the CLASS program, a national long-term care insurance program funded by payroll deductions. The reform legislation will have a significant impact on the way that individuals access health insurance, but Medicaid will retain a considerable role in the delivery of long-term care. Health reform specifically includes programs and policies intended to continue the transition from institutional care to home and community-based services, such as:

- **The Community First Choice Option:** a new option for states to provide attendant care supports to individuals living in the community with increased federal funding;
- **Money Follows the Person:** the legislation extended the timeframe of the grant program and increased the funding. The additional time and resources will allow a longer period for existing grants, and the opportunity

⁵ Congressional Budget Office. *Cost Estimate of H.R. 4872, Reconciliation Act of 2010*. <http://www.cbo.gov/ftpdocs/113xx/doc11379/AmendReconProp.pdf>

⁶ Copeland, CW. *Regulations Pursuant to the Patient Protection and Affordable Care Act (P.L. 111-148)*. Washington, DC: Congressional Research Service.



for new states to apply for funding.⁷ The Money Follows the Person program provides federal funding to assist states transition individuals from institutional settings into home and community-based services;

- **Oversight and Assessment of the Administration of Home and Community Based Services:** the legislation directs the Department of Health and Human Services to issue regulations that improve the ability of states to provide LTSS that promote the independence and self direction of beneficiaries, and that increase the coordination of services across providers;⁸ and
- **The CLASS Act:** health reform creates a voluntary, national, payroll-deduction funded long-term insurance program. The CLASS Act will provide home and community based long-term care to individuals who pay into the system for at least five years. Eligibility for the services will be determined based upon an individual's ability to perform ADLs, and will not require an income or resource test.⁹

While the full scope of these programs and initiatives will not be fully known until regulations are issued, the underlying goals are intended to support the transition of individuals from institutional to home and community-based care, and to improve the self-direction and community integration of individuals in long-term care settings. As states continue to reform and rebalance their long-term care systems, the issue of employment and independence will remain a significant policy issue. Medicaid recipients will continue to benefit from a comprehensive approach to the integration of medical and community supports, including the overlap between long-term care, employment, and community integration. Medicaid Infrastructure Grant staff members, professionals in disability services, and employment providers can further this approach through policy and program development, service coordination, and funding requirements that support their state's goals.

This report was developed by Doug Stone, a technical consultant to the Center for Workers with Disabilities. CWD is a technical assistance center dedicated to supporting states as they develop or enhance work supports and incentives for persons with disabilities. CWD is a project of the National Association of State Medicaid Directors.

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⁷ CMS website, State Medicaid Directors Letter: <http://www.cms.gov/smdl/downloads/SMD10012.pdf>

⁸ P.L. 111-148

⁹ Ibid