



Medicaid's Role in Providing Assistance with Long-Term Services and Supports

Key Points

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- Medicaid plays a major role in financing long-term services and supports (LTSS) for individuals who are functionally impaired, disabled, and critically ill, accounting for 61 percent of total national spending on LTSS in fiscal year (FY) 2012. This role will likely increase as the population ages and more individuals with disabling conditions live longer.
- Medicaid enrollees who use LTSS are a diverse group, from young to old, with many different types of physical, cognitive, and mental disabilities. They include:
 - working adults with significant physical disabilities,
 - children who are medically fragile,
 - individuals age 65 and older,
 - people with intellectual and developmental disabilities, and
 - individuals who are severely mentally ill.
- Patterns of use vary considerably across different subpopulations of LTSS users. For example, individuals dually enrolled in Medicare and Medicaid have high per enrollee spending on institutional LTSS. Non-dually enrolled individuals are more likely to use home and community-based services (HCBS).
- Although LTSS users make up a small portion of total Medicaid enrollees—just over 6 percent in FY 2010 these individuals account for almost half of all Medicaid spending.
- Medicaid LTSS is not a system that was purposefully built, but rather one that evolved over time out of legacy programs that were designed to meet the needs of different populations, differing state approaches to policy, court decisions, client advocacy, and changing ideas about where and how LTSS should be provided. The resulting patchwork of services and eligibility policies—which differ by state, enrollee group, statutory authority, and other factors—determines what services enrollees ultimately receive.
- While flexibility in LTSS benefit design and payment methods have allowed states to target groups of enrollees and to test new models, the broad array of programs and the lack of standardization make it difficult to determine which strategies best manage costs and improve the efficiency and effectiveness of care.
- MACPAC's future work on Medicaid LTSS will focus on building a better understanding and moving policy in the direction of a more efficient and effective system of LTSS. This includes examining the design and policy issues associated with the movement to managed long-term services and supports (MLTSS), studying the use of HCBS waivers, assessing the merits of moving to standardized functional assessments for Medicaid LTSS, and analyzing how to improve data on LTSS to support policy analysis, evaluation, and future program design.



Medicaid's Role in Providing Assistance with Long-Term Services and Supports

One of the distinguishing features of the Medicaid program is its major role in financing long-term services and supports (LTSS) for populations who are functionally impaired, disabled, and critically ill. LTSS generally focus on maintaining (and sometimes improving) functioning, for example, providing assistance with basic tasks of everyday life, such as bathing or dressing, or with skills related to independent living such as preparing meals and managing money. Some are provided in institutional settings such as nursing homes, others in the community. They may be needed on a regular or occasional basis, for a few months or for many years.

Medicaid is the primary payer for LTSS in the United States, and as the population ages and technology allows persons with disabilities to live longer, its role in the provision of these services will likely increase. In 2012 Medicaid accounted for 61 percent of total national spending on LTSS—\$134.1 billion (O'Shaughnessy 2014).

When it comes to LTSS, there are no simple solutions and no single path to a more efficient and effective system of high-quality care for a highly diverse population that includes frail individuals age 65 and older, adults and children with physical disabilities, persons with intellectual disabilities, and individuals who are severely mentally ill. Medicaid policies are extraordinarily complex, reflecting the program's evolution from an era in which most persons with disabilities resided in institutions to one where services are increasingly provided elsewhere, and responsibilities for administration are sometimes shared among multiple state agencies.

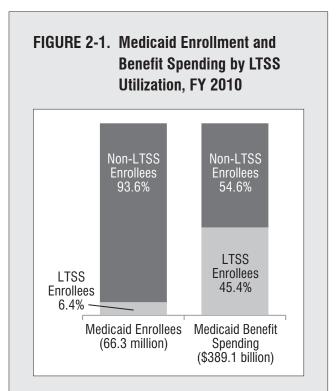
This system was not purposefully built, but rather evolved over time from public programs that primarily cared for poor and disabled populations living in institutional settings. New eligibility pathways and different types of benefits have been created, particularly through waiver programs designed to provide alternatives to institutional care. States have tailored their eligibility policies and applied for waivers to manage the number of individuals served and the breadth of services covered.

Enrollees who use LTSS are a diverse group, from young to old, with many different types of physical, cognitive, and mental disabilities. They include, among others: working adults with significant physical disabilities; children who are medically fragile and dependent on sophisticated medical technology, as well as those with autism spectrum disorders; individuals age 65 and older with advanced stages of dementia or multiple chronic conditions; people with intellectual disabilities; and those with severe mental illness. They use different types and mixes of LTSS. Their use of acute care services also varies, and they have different levels of family support. Like other Medicaid enrollees, most of these individuals have modest incomes. Some depleted their personal savings paying out of pocket for these services before becoming eligible. Others continue to spend down their income each month, helping to provide for some of the cost of their care in institutional and community settings.

The number of LTSS users overall, and those covered by Medicaid, is increasing. The number of older Americans is expected to more than double by 2050, with many people living longer (Census Bureau 2010). With advancing age comes the likelihood of increased disability, frailty, and chronic illness. The prevalence of other conditions that often require LTSS—such as autism spectrum disorder—have also been increasing over time independent of age (CDC 2014). In addition, people born with developmental or other disabilities or who suffer incapacitating injuries such as traumatic brain injury—have greatly improved survival rates, but may need assistance throughout their lives.

In this report, MACPAC has turned its attention to better understanding how Medicaid enrollees use LTSS. This inquiry arises from several concerns. First, although LTSS users make up a small portion of total Medicaid enrollees, they account for a substantial share of Medicaid expenditures. In fiscal year (FY) 2010, just over 6 percent of all Medicaid enrollees used LTSS, and total Medicaid spending on these individuals accounted for almost half of all Medicaid spending (Figure 2-1). Their LTSS spending was high, at a per full-year equivalent (FYE) enrollee average of \$31,989 (out of an average of \$45,753 for all Medicaid services, including acute-care services) (MACPAC 2014a). With the aging of the population and the growth in Medicaid enrollment among individuals who qualify on the basis of a disability, these costs are expected to grow, creating new stresses on state and federal budgets.

Second, these expenditure patterns reflect the experience of vulnerable individuals with significant needs for medical care and high use of costly, intensive, and ongoing supportive services



Notes: LTSS refers to long-term services and supports. FY refers to fiscal year. Medicaid enrollees include individuals dually eligible for Medicaid and Medicare. Expenditures are for enrollees who used any LTSS and include expenditures for both acute care and LTSS. Medicaid benefit spending from MSIS has been adjusted to match CMS-64 totals based on the methodology described in Section 5 of MACStats in MACPAC's June 2013 report to the Congress. Amounts in the June 2014 MACStats differ and are not directly comparable to those shown here because they reflect more recent (FY 2011) data and an update to the methods used to adjust benefit spending; see Section 5 of the June 2014 MACStats for details.

Sources: MACPAC analysis of Medicaid Statistical Information System (MSIS) annual person summary (APS) data as of September 2013 and CMS-64 Financial Management Report (FMR) net expenditure data as of May 2013.

such as personal care, home health care, therapies, and long-stay institutional care that are not usually covered by any payer except Medicaid. One of the key challenges is how to support their care and to provide the most cost-effective and high-quality services to these enrollees.

Given the significant spending on LTSS and the likelihood that it will continue to drive Medicaid budgets, policymakers are searching for ways to manage costs and to improve the efficiency and effectiveness of care. In addition, they are seeking to address enrollees' preferences and comply with the Supreme Court's 1999 decision in Olmstead v. L.C. to furnish services in the most integrated setting appropriate to an individual's needs by shifting service delivery away from institutions to home and community-based settings. They are also looking at how to better integrate acute care and LTSS and how to better match services to the needs of individuals with different types of disabilities and for whom there are likely to be different goals for care.

As MACPAC considers how the Medicaid program is serving high-cost, high-need enrollees, this chapter looks at one slice of this population and their experience—focusing on the policies and practices affecting access to and use of LTSS. MACPAC's work here is primarily descriptive, building a knowledge base about these individuals and how they interact with the Medicaid program.

The chapter begins by describing the evolution of Medicaid's role in providing LTSS. Medicaid policies affecting LTSS users have become increasingly complex over the years, with services financed and delivered in a siloed rather than an integrated manner. Over time, new programs and benefits have been added. Legal decisions have established rights for persons with disabilities and fostered a transition away from institutional settings, and multiple state agencies have become involved in the administration of the program. As a result, the overall design of Medicaid's approach to financing LTSS has become less coherent. While each element has a rationale and backstory, as a whole, it appears more accidental than systematic.

The chapter then describes LTSS users along several dimensions: how they become eligible for Medicaid, the types of services they use, and their use of services. Understanding who currently uses Medicaid LTSS, their routes to eligibility, and the extent to which policies for eligibility and coverage of benefits affect the services they receive is a necessary first step in considering how to create more rational, equitable, and effective policy for the future.

Although MACPAC has reported in the past on how Medicaid works for people with disabilities both those enrolled only in Medicaid and those dually enrolled in Medicare and Medicaid—this is a first step in MACPAC's inquiry specific to LTSS. The chapter concludes with a discussion of policy areas that the Commission will explore in greater depth in the months ahead.

Medicaid LTSS: Program or Patchwork?

Medicaid LTSS rules for eligibility, covered benefits, and access to services vary substantially across states and among the populations receiving care. This system evolved over time from legacy programs designed to meet the needs of different populations, differing state approaches to policy, court decisions, client advocacy, and changing ideas about where and how LTSS should be provided.

When enacted, Medicaid LTSS were almost exclusively provided to public assistance recipients in institutions. Over time, there was a shift in federal policies allowing coverage of individuals who did not receive public assistance but who had extremely high medical expenses. With this shift, states were able to extend coverage to individuals and families who did not previously meet public welfare requirements (i.e., those who were not aged, blind, disabled, or families with dependent children) but whose spendable income was above the level permitted for cash assistance but did not exceed 133 percent of the public assistance standard. These three populations (aged, blind, and disabled) still account for the majority of Medicaid LTSS spending on both institutional and home and community-based services (HCBS), primarily through the personal care option, the HCBS waiver program, and the home health benefit.

The following section describes the ways in which many factors contribute to the increasing complexity of the LTSS landscape for the heterogeneous population of LTSS users. These factors include waivers, federal policy, litigation and the distribution of administrative responsibilities.

Waivers. New programs or benefits were added to respond to the concerns of specific LTSS users. In particular, in 1981, Section 1915(c) HCBS waivers were established to allow states to provide LTSS to enrollees in community-based settings. Most Medicaid HCBS are now provided under waiver authority. Waiver programs allow states to provide specific HCBS to targeted populations, cap enrollment, and to require mandatory enrollment in managed care for exempt populations. The eligibility requirements, services available, and operational elements of HCBS waivers are described later in the chapter.

The proliferation of waivers, however, can be administratively burdensome for states and may in some cases confuse enrollees who do not know the tradeoffs in benefits of various waiver programs for which they might be eligible. States are able to consolidate multiple waivers under either Section 1915(c) or Section 1115 waiver authority (CMS 2014a). Given the ability to combine multiple existing waiver programs into fewer waivers and new authority to provide HCBS under a state plan, states have options to reduce this complexity. However, states continue to weigh the flexibility offered by waivers in targeting populations against the administrative complexity of managing multiple waivers.

The complexities of implementing HCBS waivers make it hard to understand the use of such waivers across the entire Medicaid program. For example, Medicaid claims data do not always contain clear information about the specific services provided under waivers. In addition, basic information, such as functional eligibility thresholds and other cost containment strategies (e.g., whether and how a state maintains waiting lists for waiver services) are contained within waiver documents and other subregulatory policies that are challenging to catalogue. Finally, subregulatory guidance may be implemented inconsistently, which could result in some previously approved practices being disapproved at later points.

Federal legislation. Recent federal laws have expanded access to Medicaid HCBS. For example the Deficit Reduction Act of 2005 (DRA, P.L. 109-171) created the Money Follows the Person (MFP) demonstration grant program, which provided states with additional resources to transition individuals from institutions to HCBS. This legislation also allowed states to provide HCBS under the Medicaid state plan without obtaining a waiver under Section 1915(c) (§1915(i) of the Social Security Act (the Act)).

The Patient Protection and Affordable Care Act (ACA, P.L. 111-148 as amended) also expanded eligibility further and allowed states to provide Medicaid LTSS to more individuals in a community setting. For example, the Community First Choice (CFC) program (§1915(k) of the Act) gives states the option of providing HCBS to individuals who are eligible for Medicaid and have incomes below 150 percent of the federal poverty level (FPL) but who may not meet institutional level-of-care (LOC) criteria, or those with institutional LOC needs whose incomes exceed 150 percent FPL (CMS 2011). The ACA also includes the Health Homes option, extension and modification of the MFP demonstration, establishment of the state Balancing Incentive Payments (BIP) program, and others (§1945 of the Act and §2403, §10202 and §2602 of the ACA).

These options provide states with new mechanisms for providing LTSS and for those that increase the proportion of spending on certain LTSS to receive enhanced federal matching payments. As of 2013, all but three states plan to pursue or are pursuing at least one ACA option, but it is too early to determine the full impact of the various LTSS options on spending and beneficiary outcomes (O'Shaughnessy 2013).

Litigation. Legal decisions, such as the Supreme Court *Olmstead v. L.C.* ruling in 1999, have also shaped the complex LTSS landscape. The *Olmstead* decision interpreted Title II of the Americans with Disabilities Act (ADA, P.L. 101-336) and its implementing regulations that oblige states to administer their services, programs, and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (28 CFR 35.130(d)). States must now operate public programs (including Medicaid) in a non-discriminatory fashion and furnish services in the most integrated setting appropriate to an individual's needs, requiring placement of persons with disabilities in community settings rather than institutions.

The *Olmstead* ruling on state LTSS policies has been a major factor in the increased use of HCBS. The national share of Medicaid spending on HCBS has more than doubled from 20 percent of Medicaid LTSS spending in 1995 to 45 percent of Medicaid LTSS spending in 2011 (KCMU 2014a).

Other federal court decisions have clarified states' responsibilities related to LTSS. Federal courts have ruled consistently that the ADA's protections apply to persons living in the community, not just to persons already institutionalized. The suits filed under the ADA have reinforced states' obligations to operate state Medicaid programs in a way that does not lead to unnecessary institutionalization (NSCLC 2010).

In challenges related to the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit, courts have ordered state Medicaid agencies to develop and provide specific types of LTSS (e.g., intensive community-based mental health services) for enrollees.1 Further, both in class actions and individual actions, courts have ordered Medicaid agencies to provide a certain level of Medicaid benefits beyond what was originally granted by the agency.² And although the Medicare program plays a much smaller role in providing LTSS than does Medicaid, a recent case affecting Medicare coverage of skilled care services (Jimmo v. Sebelius) raises questions about the extent to which Medicaid and Medicare will be responsible for covering such services to those dually enrolled in both programs.³

Medicaid LTSS have been affected by other federal litigation. For example, the Civil Rights of Institutionalized Persons Act (P.L. 96-247) authorizes the Attorney General of the United States to investigate conditions at certain residential institutions operated by state governments—including Medicaid-funded LTSS facilities. This law has resulted in multiple settlement agreements between the U.S. Department of Justice and states that required changes to certain elements of the Medicaid LTSS benefits offered by the states (DOJ 2012).

Shared administrative responsibility. The provision of Medicaid LTSS also differs by state because administration may be shared among multiple state agencies. Under federal regulations, the Medicaid agency is responsible for ensuring that LTSS is operating in accordance with federal requirements (42 CFR 431.10), even if LTSS may be operated by another state agency. Agreements among agencies specify the delegation of administrative and operational activities and functions that the other agency can perform under the supervision of the Medicaid agency. State agencies involved in LTSS typically include offices

on aging, developmental disabilities agencies, and mental health authorities for the populations under their jurisdiction. (For state specific details, see Appendix Tables 2-A-1, 2-A-2, and 2-A-3.)

In some states, the agency operating the LTSS program is overseen by the Medicaid agency and may be a division or department within the Medicaid agency. In other states, the Medicaid agency may delegate responsibility to the LTSS agency while still ensuring that the LTSS agency meets specific federal and state reporting requirements and expectations. In such cases, the Medicaid agency serves primarily to provide oversight, passing funds through to the LTSS agency with a minimal role in operations. Separate agencies may also work alongside state Medicaid agencies to deliver targeted services (e.g., behavioral health services) to certain enrollees.

State agencies that serve specific populations with disabilities, or persons with specific diseases or conditions (e.g., HIV/AIDS, hemophilia) may also provide non-Medicaid LTSS to Medicaid enrollees. This, in turn, likely affects which LTSS Medicaid enrollees use. For example, some state developmental disability agencies provide respite services to family caregivers, allowing some Medicaid enrollees to stay in the community and receive LTSS. State mental health agencies often manage and provide certain LTSS in congruence with the state Medicaid agency and administer substance abuse and mental health block grants that provide services to individuals who may also have Medicaid coverage. Enrollees with HIV/ AIDS may also receive services provided through state agencies that operate the Ryan White program, which provides support services to individuals and families affected by the disease, and may fill coverage gaps where benefits are limited (KFF 2013).

How Do Medicaid Enrollees Qualify for LTSS?

Medicaid policies determining eligibility focus on finances (income and assets) and measures of functional status, rather than the existence of a specific clinical condition. In other words, people become eligible because they have low incomes and assets and meet specific thresholds for clinical and functional impairment, not because they have, for example, particular physical or mental disabilities. Measures of functional status are referred to as LOC criteria.⁴ These standards are set by states within federal guidelines (Table 2-1).⁵

Some enrollees who have slightly higher incomes than their state's financial eligibility income thresholds expend (spend down) their income on medical expenses to qualify for Medicaid. Studies have shown that just under 10 percent of the previously non-Medicaid eligible population has spent down to qualify for Medicaid. Of those Medicaid enrollees who spent down, over half (51.4 percent) used LTSS, including either HCBS or institutional services (Wiener et al. 2013).

Eligibility policies also dictate, to some extent, the services to which enrollees are entitled. States have considerable flexibility in setting specific eligibility standards and covered benefits. Thus, for each of the eligibility pathways described below, an individual may be entitled to different Medicaid LTSS benefits as determined by the state.

Changes made under the ACA to simplify eligibility and enrollment processes for many Medicaid eligibility pathways do not apply to LTSS pathways. Unlike populations now subject to the new simplified modified adjusted gross income (MAGI) methodology, individuals qualifying on the basis of disability or age (65 and older) must still provide documentation of income and assets in order to be determined financially eligible for Medicaid services, including LTSS, thus requiring states to

		Group S					Full State	Institutional Long- Term Services and Supports (LTSS)	Home and Community Based (HCBS Waiver
Eligibility Pathway	65+	19–64	Less than 19	Functional Assessment Criteria	Income Threshold	Income Disregards	Plan Benefits	Conditional upon	
Supplemental Security Income (SSI)-Related	Yes	Yes	Yes	Adults 65+: None; Adults 18–65: Blindness or permanent, medically determinable impairment that results in the inability to do any substantial gainful activity	73% FPL	First \$20 of unearned monthly income; first \$65 of monthly earned income; half of earned income above the first \$65	Yes	NF: Yes; all other institutions at state option	At state option
				Children <18: Permanent, medically determinable impairment that results in marked and severe functional limitations	Children <18: 109%–226% FPL	Children <18: Living expenses for parents and siblings, other parental income deductions		Children <18: Yes, medically necessary including H	under EPSDT,
Poverty-Related	Yes	Yes	Yes	Same as SSI	up to 100% FPL	Same as SSI	Yes	NF: Yes; all other institutions at state option	At state optior
Medicaid Buy-In (MBI)									
BBA 97 Eligibility group	No	Yes	16–18 only	Same as SSI	up to 250% FPL		Yes	At state option	At state option
Basic Eligibility group	No	Yes	16–18 only	Same as SSI	State-defined limit above 250% FPL	States may disregard	Yes	At state option	At state option
Medical Improvement group	No	Yes	16–18 only	Must have a "medically improved" disability (based on SSI disability determination)	up to 250% FPL	additional income and resources	Yes	At state option	At state optior
Family Opportunity Act (FOA)	No	No	Yes	Same as SSI	up to 300% FPL		Yes	At state option	At state option
Medically Needy (MN)	Yes	Yes	Yes	Same as SSI	State-established income threshold	Spend down amount based on individual's medical expenses, income and state-established budget period	At state option	At state option	At state option
Special Income Level (SIL)	Yes	Yes	Yes	State-established LOC for NF, ICF/ID, or hospital	up to 300% SSI	If MN pathway not available, then any amounts above SIL limit that are placed in a Miller Trust	Yes	At state option	At state option
TEFRA/ Katie Beckett	No	No	Yes	State-established LOC for NF, ICF/ID, or hospital	No more than the income limits to receive Medicaid institutional LTSS	Parental income and resources are disregarded	Yes	No	At state option
1915(i) State-Plan HCBS	Yes	Yes	Yes	State-established LOC less than for NF, ICF/ID, or hospital	up to 150% FPL	States may use institutional deeming and spousal impoverishment to disregard parent or spousal income	At state option	No	At state option

TABLE 2-1. Eligibility Criteria for Selected Medicaid Eligibility Pathways

Notes: For enrollees receiving institutional or home and community-based services (HCBS) long-term services and supports (LTSS) through a waiver under any eligibility pathway, states have the option to disregard parent or spousal income and to allow enrollees to retain income under personal needs allowances or monthly maintenance needs allowances. LOC criteria refers to level-of-care criteria. FPL is federal poverty level, which is \$11,760 for an individual in 2014. NF is nursing facility. EPSDT is Early and Periodic Screening, Diagnostic, and Treatment services. ICF/ID is intermediate care facility for individuals with intellectual or developmental disabilities. TEFRA is the Tax Equity and Fiscal Responsibility Act (PL. 97-248).

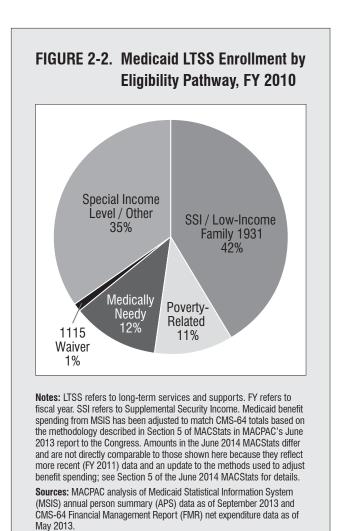
Sources: HRTW National Resource Center 2013, SSA 2013a, Stone 2011.

continue to run two administrative systems to determine Medicaid eligibility.

Supplemental Security Income-related

eligibility. About two in five (42 percent) of Medicaid enrollees who used LTSS in FY 2010 enrolled through the Supplemental Security Income (SSI)-related eligibility pathway (Figure 2-2). Nondually eligible enrollees who used LTSS were more likely to enter through the SSI-related eligibility pathway (62 percent) than LTSS users who were dually enrolled in Medicaid and Medicare (33 percent). (More discussion about LTSS users by dual eligibility status can be found below.)

SSI is a federal income support program for people with limited income and resources who are age 65 or older, blind, or have disabilities. To qualify, these



individuals may have countable monthly income of no more than the federal benefit rate, which is \$721 in FY 2014 (SSA 2013a). In all but 10 states, individuals eligible for SSI are automatically eligible for Medicaid, including LTSS offered under the state plan (if they meet specific functional eligibility criteria) (Table 2-2). The remaining 10 states-known as 209(b) states-have established more restrictive criteria (either income and asset thresholds or functional eligibility criteria) than SSI.6 Enrollees must generally meet SSI's functional eligibility standards, which include being age 65 or older; or, for adults age 18 to 64, having a significant impairment that impedes their ability to do any gainful work; or, for children under the age of 18, having a significant impairment that results in marked or severe functional limitations to their ability to work (SSA 2013a) (Table 2-1). States may have the U.S. Social Security Administration (SSA) determine eligibility for Medicaid at the same time that it determines whether an individual meets the financial standards and disability requirements for SSI. Alternatively, a state may use the SSA financial and functional criteria to determine whether an individual qualifies for Medicaid on the basis of disability (SSA 2013b).7

States are only required to provide nursing facility and home health services to those considered eligible for Medicaid due to their receipt of SSI, so long as they meet LOC criteria (ASPE 2010). States may provide SSI enrollees additional LTSS (optional under the state plan or in a waiver) as long as they meet any targeting or LOC criteria established by the state for the particular service.

Poverty-related eligibility. Just 11 percent of Medicaid enrollees who used LTSS in FY 2010 received coverage through the poverty-related eligibility pathway (Figure 2-2). This is an optional pathway allowing the state to cover LTSS for individuals with incomes up to 100 percent FPL who have disabilities or are over age 65.⁸ This pathway (as well as the Medicaid buy-in (MBI) and medically needy eligibility pathways discussed

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State	SSI-Related	Poverty- Related	Medicaid Buy-In²	Medically Needy	Special Income Level	§1915(i) HCBS ³	Katie Becket
Total	51	24	37	35	43	12	27
Alabama	\checkmark				\checkmark		
Alaska	\checkmark		\checkmark		\checkmark		\checkmark
Arizona	\checkmark	\checkmark	\checkmark		\checkmark		
Arkansas	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark
California	\checkmark	\checkmark	\checkmark	1		\checkmark	1
Colorado	1				\checkmark	√ 	√
Connecticut ¹	1		\checkmark	\checkmark	√ √	V	, ,
Delaware	√ √		v	v	↓ ✓	v	√ √
District of Columbia	✓ ✓	\checkmark		\checkmark	✓ ✓		v
Florida	✓ ✓	✓ ✓			✓ ✓	\checkmark	
	✓ ✓	V		\checkmark	✓ ✓	V	1
Georgia		,			\checkmark		\checkmark
Hawaii ¹	1	\checkmark	,	\checkmark	,	,	,
Idaho	\checkmark		\checkmark		\checkmark	\checkmark	\checkmark
Illinois ¹	\checkmark	\checkmark	\checkmark	\checkmark			
Indiana	\checkmark	\checkmark	\checkmark		\checkmark		
lowa	\checkmark		\checkmark	\checkmark	\checkmark	\checkmark	\checkmark
Kansas	\checkmark		\checkmark	\checkmark	\checkmark		
Kentucky	\checkmark			\checkmark	\checkmark		\checkmark
Louisiana	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	
Maine	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark
Maryland	\checkmark		\checkmark	1	√ 		
Massachusetts	1	\checkmark	v V	, ,	↓ ✓		\checkmark
Michigan	✓ ✓	✓ ✓	✓ ✓	<i>✓</i>	✓ ✓		✓ ✓
Minnesota	✓ ✓	✓ ✓	✓ ✓	✓ ✓	✓ ✓		✓ ✓
Mississippi	✓ ✓	v	v	v	✓ ✓		
Missouri ¹		/					V
	1	\checkmark		1	\checkmark	,	
Montana	\checkmark			1		\checkmark	
Nebraska	\checkmark	\checkmark	\checkmark	\checkmark			\checkmark
Nevada	\checkmark		\checkmark		\checkmark	\checkmark	\checkmark
New Hampshire ¹	\checkmark		\checkmark	\checkmark	\checkmark		
New Jersey	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		
New Mexico	\checkmark		\checkmark		\checkmark		
New York	\checkmark	\checkmark	\checkmark	\checkmark			\checkmark
North Carolina	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	
NorthDakota ¹	\checkmark		\checkmark	\checkmark			
Ohio ¹	1		1	1	\checkmark		\checkmark
Oklahoma ¹	√ √	1	v	✓ ✓	✓ ✓		✓ ✓
Oregon	\checkmark	v	1	v	\checkmark	\checkmark	\checkmark
Pennsylvania		1	✓ ✓	1		V	v
Rhode Island	1	<i></i>			\checkmark		,
	1	√ √	\checkmark	\checkmark	\checkmark		\checkmark
South Carolina	1	\checkmark			\checkmark		
South Dakota			\checkmark		\checkmark		\checkmark
Tennessee	\checkmark				\checkmark		
Texas	\checkmark		\checkmark		\checkmark		
Utah	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		
Vermont	\checkmark		\checkmark	\checkmark	\checkmark		\checkmark
Virginia ¹	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		
Washington	1		1	1	\checkmark		
West Virginia	√ √		√ √	<i>✓</i>	\checkmark		\checkmark
	√ √		✓ ✓	✓ ✓	✓ ✓	\checkmark	✓ ✓
Wisconsin	./		./	./		./	./

TABLE 2-2. Medicaid Long-Term Services and Supports Eligibility Pathways by State

Notes: SSI refers to Supplemental Security Income. HCBS refers to home and community-based services.

1 SSI-related pathways include 209(b) states using more restrictive eligibility criteria than SSI.

2 Medicaid buy-in (MBI) includes any of the three MBI groups (Balanced Budget Act of 1997 Group, Basic Eligibility Group, and Medical Improvement Group).

3 States may use Section 1915(i) as a separate eligibility pathway with access to existing state plan HCBS, Section 1915(c) HCBS waiver services, or specific services included in Section 1915(i) benefits. States shown include states with approved state plan amendments that include either benefits or eligibility groups. Sources: MACPAC 2014b, NASUAD 2013, Stone 2011.

below) also uses the SSI functional eligibility criteria (Table 2-1). Like SSI-related enrollees, these enrollees are entitled to full Medicaid benefits, including state plan LTSS if the individual meets the state's LOC or targeting criteria.

States may extend HCBS authorized under a waiver to those eligible under the poverty-related pathway. In FY 2014, 24 states chose to provide Medicaid coverage to persons who are 65 and older or disabled whose incomes were below the poverty level but above the SSI or 209(b) level (MACPAC 2014b) (Table 2-2).

Medicaid buy-in. States have the option to cover individuals with disabilities who work and have incomes too high to qualify for Medicaid. In 2009, 37 states offered Medicaid to individuals with disabilities under at least one of three MBI pathways (Stone 2011):

- Balanced Budget Act of 1997 (BBA 97) Eligibility Group. States may use this option to cover individuals whose income does not exceed 250 percent FPL. In 2011, 16 states included this group in their MBI (Kehn 2013).
- Basic Eligibility Group. States may use this option to cover individuals above 250 percent FPL and whose income does not exceed a state-defined limit. This is the most frequently included group; 21 states included this group in their MBI in 2011 (Kehn 2013).
- Medical Improvement Group. States may use this option to cover individuals who would be in the Basic Eligibility Group, except for the fact that their disability no longer meets the SSI definition or that they work at least 40 hours per month. States include this group in their MBI less frequently than the other two groups; only eight states opt to cover this group (Kehn 2013).

There is a separate buy-in program for children with disabilities whose family income is too high to qualify for Medicaid. This option is referred to as the Family Opportunity Act (FOA) pathway, although it functions similarly to MBI. The FOA was established by the DRA and gives states the option to allow families with incomes up to 300 percent FPL to purchase Medicaid coverage for their children with disabilities under age 19 (Stone 2011).

The MBI pathway entitles enrollees to full Medicaid benefits, including state plan LTSS. States may extend HCBS waiver benefits to individuals eligible under this pathway if they meet level-ofcare criteria. States may also impose a monthly premium or other cost-sharing requirements (discussed below).

Medically needy. Twelve percent of Medicaid LTSS users are eligible under the medically needy pathway that allows states to cover individuals age 65 and older or individuals with disabilities with high medical expenses relative to their income once they have spent a portion of their excess income on their medical expenses (referred to as the spend-down requirement) (Figure 2-2). For both dually enrolled and non-dually enrolled LTSS users, those who came through the medically needy eligibility pathway had the highest LTSS spending per enrollee of any eligibility group (Table 2-4 and Table 2-5).

The income threshold and the budget period used in medically needy eligibility determinations are state-specific. States may offer full Medicaid or a more limited set of state-specified benefits to this group. They may also provide institutional LTSS and HCBS waiver benefits to those meeting LOC criteria. In 2014, 35 states had a medically needy pathway (MACPAC 2014b) (Table 2-2).

Special income level. Many Medicaid LTSS users come through the special income pathway under which states may cover individuals age 65 and older or individuals with disabilities who meet LOC criteria for certain institutions and have incomes up to 300 percent of the SSI benefit rate.⁹ LTSS users dually enrolled in Medicaid and Medicare were much more likely to come through the special income level pathway (1.2 million out of 2.9 million total or 43 percent) compared to non-dually enrolled LTSS users (229,000 out of 1.4 million total or 17 percent) (Table 2-4 and Table 2-5). In 2014, 43 states offered Medicaid coverage to individuals through this pathway (MACPAC 2014b) (Table 2-2).

Functional eligibility for this pathway (as well as Tax Equity and Fiscal Responsibility Act (TEFRA)/Katie Beckett, and Section 1915(i) state plan HCBS discussed below) is determined using the state-established LOC criteria that typically require enrollees to need institutional-level services and supports (Table 2-1). States may provide institutional LTSS and HCBS waiver benefits to individuals meeting LOC criteria to this group.

TEFRA/Katie Beckett. The TEFRA/Katie Beckett pathway provides Medicaid eligibility to children with severe disabilities whose family income would ordinarily be too high to qualify for Medicaid. This pathway was created to address the fact that Medicaid policies originally did not count parental income toward the child's Medicaid eligibility if that child was institutionalized in a hospital, nursing home, or an intermediate care facility for individuals with intellectual or developmental disabilities (ICF/ID) for 30 days or more, but would count such income if the child was at home. Families of such children could get Medicaid coverage only by placing their child in an institution, becoming impoverished, or relinquishing custody. In 1982, TEFRA (P.L. 97-248) created an exception that allowed severely disabled children, like Katie Beckett for whom the provision was named, to receive their care at home while retaining their Medicaid coverage (Smith et al. 2000). Under this pathway, states may elect to count only the income and financial resources of a child with a disability who needs LTSS. States may provide institutional LTSS or HCBS waiver

benefits to individuals eligible under this pathway who meet the level-of-care criteria. Twenty-seven states used the Katie Beckett option in 2009 (Stone 2011) (Table 2-2).

Section 1915(i) state plan HCBS. Section 1915(i) of the Act allows states to offer HCBS as part of the Medicaid state plan to individuals with incomes up to 150 percent FPL. The ACA amended this section to create a new eligibility pathway for individuals with disabilities who are not otherwise eligible for Medicaid and do not require an institutional level of care. Under the amended Section 1915(i), states may now offer full Medicaid coverage to individuals eligible under this pathway, and they may extend this pathway to individuals with income up to 300 percent of SSI who are receiving Section 1915(c) HCBS waiver services (Stone 2011). As of November 2013, 12 states had received approval of Section 1915(i) state plan amendments and 4 states were awaiting approval of submitted state plan amendments (NASUAD 2013) (Table 2-2).10

Enrollee contributions to the cost of Medicaid LTSS. In contrast to other aspects of the Medicaid program, most states do not set maximum income limits for those seeking Medicaid coverage of LTSS. This is not to say, however, that wealthy individuals are able to shelter assets or avoid spending their own resources on LTSS. Federal rules prohibit potential LTSS users from transferring assets such as homes or bank accounts to relatives in order to qualify for Medicaid.¹¹ In addition, states use a variety of different policies to ensure that Medicaid LTSS users contribute to the costs of their care, albeit without requiring that individuals impoverish themselves or their families. These include:

Cost sharing. States may impose a monthly premium or other cost-sharing requirements for enrollees who come through certain eligibility pathways or use certain LTSS benefits (such as nursing facilities) (ASPE 2010). Individuals qualifying through the medically needy eligibility pathway must have applied a portion of their income to medical expenses in order to meet state-specified spend-down requirements.

- Personal allowances. States must establish monthly levels of income that an LTSS user may retain to cover the cost of certain personal expenses after fulfilling any costsharing requirements. Enrollees using either institutional or HCBS LTSS may retain a monthly allowance to pay for goods and services not provided by the facility or covered by Medicaid (e.g., clothing or room and board costs of HCBS users).¹²
- Income disregards. Medicaid law allows states to adopt rules that would prevent the impoverishment of a spouse of a Medicaid beneficiary receiving LTSS (§1924 of the Act). Under these rules, states establish the amount of assets a spouse residing in the community may retain, which must be no less than \$23,448 and cannot exceed \$117,240 in countable assets in 2014 (CMS 2014b). Additionally, the law exempts a community-residing spouse's income for the purposes of Medicaid eligibility and allows the institutionalized spouse to transfer income to a limited-income community spouse, up to a state-determined maximum level (but no less than \$1,939 and no greater than \$2,931 in 2014) (CMS 2014b). States may apply spousal impoverishment rules to HCBS waiver participants, and in 2009 all but five states applied these rules to their largest HCBS waiver program (Stone 2011).
- Trusts. Federal law allows for the establishment of certain trusts that may not be counted for the purposes of determining Medicaid eligibility, thereby allowing individuals with higher incomes or assets to qualify for Medicaid LTSS (§1917(d) of the Act). Miller Trusts (also known as Qualified Income Trusts)

are used in some states that offer the special income level eligibility pathway and do not have a medically needy spend-down provision. Funds placed in a Miller Trust may be used to pay the cost of the individual's care, up to a state-specified amount. Certain other trusts established under Section 1917(d)(4)(A) of the Act, or "Type A" special needs trusts, can also be established on behalf of an individual with a disability under the age of 65 in some states. In addition, in some states pooled income trusts are run by nonprofit associations on behalf of individual beneficiaries. Upon the death of the enrollee, the remaining funds in the individual account of these trusts can either be retained or paid to the state as reimbursement for any Medicaid services the individual received, depending on the trust (Stone 2011).

Which Long-Term Services and Supports Does Medicaid Cover?

There are only two mandatory LTSS benefits that must be provided under the Medicaid state plan: nursing facility and home health services. Nursing facility services are those provided by an institution offering 24-hour medical care and skilled nursing care, rehabilitation, or health-related services to individuals who do not require hospital care (MACPAC 2012). Home health services must include nursing, home health aides, and medical supplies and equipment (ASPE 2010). States may choose to provide additional therapeutic services under home health (occupational or physical therapy, speech pathology, and audiology) and determine the medical necessity criteria by which home health service utilization is managed (42 CFR 440.70(b), Smith et al. 2000).

States may cover federally defined optional longterm services and supports, either under their state plans or via waivers (Table 2-3). Once a state includes an optional service within its state plan, it must provide that service to all individuals eligible under all eligibility pathways that grant access to the traditional benefit package (Table 2-1). States may establish targeting LOC criteria for some optional services, limiting who can access certain services. Optional services include both institutional LTSS (such as ICFs/ID) and HCBS (such as personal care services) (Table 2-3).

In order to offer community-based LTSS under a waiver, states must submit a waiver application to the Centers for Medicare & Medicaid Services (CMS). That application describes the services to be provided, the target population, service eligibility criteria, and the statutory requirements the state wishes to waive (e.g., the requirement to provide comparable services to all enrollees).¹³ Waiver requests must also specify target enrollment numbers and, for Section 1915(c) waivers, must specify the participant limit, how the state will manage enrollment, and, if applicable, how the state will manage waiting lists (CMS 2008).14 Waivers must be reapproved by CMS every three to five years.15 States are required to post proposed Section 1115 demonstration waiver applications and any accompanying documents online at least 30 days prior to their submission to CMS; CMS also requires public notification of proposed changes to Section 1915(c) waivers as well (CMS 2014a, NSCLC 2012).

HCBS waivers permit states to restrict and expand coverage for LTSS in ways not permitted under their state plans, including flexibility in benefits provided to specific groups and caps on enrollment; they are the primary vehicle by which states offer HCBS. As of 2013, all but three states operate Section 1915(c) waivers (KCMU 2014a). States may operate multiple Section 1915(c) waivers, and in 2010, 284 separate waivers were providing LTSS to 1.4 million enrollees (KCMU 2014a). Other states rely on Section 1115 authority to provide LTSS to Medicaid enrollees. This includes three states that only provide LTSS under Section 1115 authority (Arizona, Rhode Island, and Vermont) and five states that include LTSS for certain populations in managed care programs operating under Section 1115 authority and provide separate Section 1915(c) HCBS waivers for other populations (KCMU 2014a).¹⁶

Although states can use HCBS state plan or waiver options to provide services in community-based settings, federal statute does not allow the Medicaid program to pay for housing for individuals who are not institutionalized (except in limited circumstances under HCBS programs) (§1915(c) (1) of the Act and 42 CFR 441.310). Some states may offer residential services under Medicaid HCBS provided in group homes or assisted living facilities to certain enrollees; however, the payment for these services does not cover the room and board costs for individuals receiving these supports.17 Individuals who access out-of-home residential services under Medicaid HCBS may do so because their state does not allow them to retain enough income or assets to pay for a residence outside of a provider-owned setting. Lack of affordable housing options has been identified as a barrier to transitioning individuals out of LTSS institutions and into community settings, which may impede state efforts to significantly rebalance LTSS systems. The interplay between the lack of affordable community-based housing and the provision of HCBS warrants careful examination when considering LTSS policy changes.

As a result of the interplay among optional pathways, state-specific definitions of financial and functional eligibility, and the design of benefits, similarly situated Medicaid enrollees may receive vastly different services in different states, and two individuals with identical LTSS needs in different states (or eligible under different pathways within a state) may ultimately use different Medicaid LTSS.

For example, among children who need LTSS, a child with autism spectrum disorder, whose family income is 100 percent FPL (\$19,790 for a family

Availability	Specific Services
State plan services	
States must provide services to all eligible	 Intermediate care facilities for individuals with intellectual and developmental disabilities
enrollees but may require enrollees to meet targeting	Mental health facilities for individuals younger than 21 or older than 65
or level-of-care (LOC)	 Personal care
criteria for state plan long-term services and	► Rehabilitation
supports (LTSS).	Targeted case management
	Private duty nursing
	Health homes for individuals with chronic conditions
	Speech, occupational, physical, or other rehabilitative and habilitative therapies
	 Section 1915(i) home and community-based services
	 Section 1915(j) self-directed personal assistance services
	 Section 1915(k) Community First Choice
	 Other services approved by the Secretary of the U.S. Department of Health an Human Services (the Secretary)
Waiver services	
States may provide	Section 1915(c) home and community-based services (HCBS):
services to individuals who are not otherwise eligible	 enable independent life in the community;
for Medicaid and may limit enrollment to individuals	 are specified in the state's waiver application, which is approved by the Secretary;
who meet state- established LOC criteria.	may not necessarily be covered for the rest of the population; and
States may also limit the number of enrollees, target	may include case management, personal care services, adult day, habilitation respite, day treatment, psychosocial rehabilitation, and others.
specific populations, or may limit the geographic	Section 1115 research and demonstration waiver services:
availability of waiver programs.	 are specified in the state's waiver application, which is approved by the Secretary;
	► may include services not typically covered by Medicaid, including HCBS; and
	may use innovative delivery systems that differ from traditional Medicaid.

Notes: Optional state plan services can vary in terms of the specific services covered; the service delivery location; and the frequency, duration and scope of services included under each optional benefit. Within waiver programs, states may craft a very comprehensive, broad benefit package or conversely, a very narrow and limited set of services. Waiver services may also include services available under the state plan, but by including duplicative services in the waiver, states may provide the services to individuals not eligible under mandatory pathways or may provide services in excess of the limits on state plan services. States also have the ability to specify unique service delivery methods, such as self-direction, available to waiver participants. HCBS can be offered in a variety of community-based settings, including in the participant's home, in residential settings such as group homes or assisted living facilities, and in other community settings such as the participant's job or day habilitation center. Appendix Table 2-A-4 lists LTSS benefits by state.

Source: MACPAC 2014b.

of three in 2014) and does not qualify for SSI, may need certain LTSS such as Applied Behavioral Analysis (ABA) and other habilitative therapies to help acquire daily living skills.

In order to receive LTSS under Medicaid, the child would have to first be determined eligible according to state rules. In Florida, the child would likely qualify for Medicaid under the poverty-related pathway; in Georgia, the child would likely qualify under the Katie Beckett pathway. In both states, ABA services are only available under state plan EPSDT benefit if the services are determined medically necessary. Other states (for example, Michigan) offer ABA through HCBS waiver programs that may have different functional eligibility criteria.

Adult Medicaid enrollees face similar circumstances. For example, an adult living in the District of Columbia with paraplegia who requires personal care services to perform many activities of daily living and works outside of his or her home, not making more than \$903 a month, can qualify for Medicaid under the poverty-related pathway and receive personal care services from Medicaid under the state plan benefit.

However, if the adult moves to another state—for example Indiana—and gets a better paying job, the individual could earn not more than \$3,160 a month and could pay a premium and other cost-sharing to get Medicaid coverage through the Medicaid buy-in pathway. Because Indiana does not include personal care services under its Medicaid state plan, the individual must be enrolled in an HCBS waiver to receive those services. If the individual were to again change his or her life situation by getting married and moving to another state, like New Hampshire, the couple could not earn more than \$4,063 per month in order to continue buying into and receiving Medicaid personal care services.

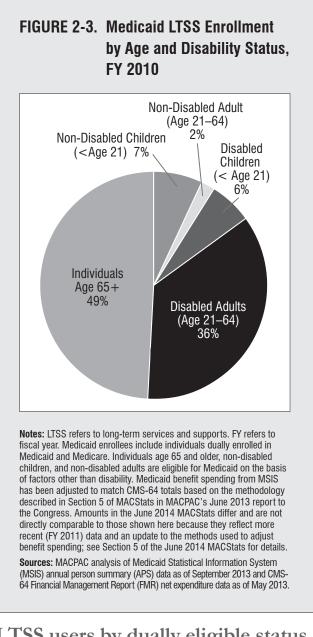
Who Uses Medicaid LTSS?

When we think about people receiving Medicaid LTSS, we think about them from the perspective of individuals: how such services contribute to their daily functioning and where they receive them. From a practical perspective, we can group them by their specific disabilities or ages, including for example, frail individuals age 65 and older or people with traumatic brain injury. And in fact, over time, Medicaid has assumed increasing responsibilities for such populations, many of whom were once primarily housed in public institutions. But for the most part, with the exception of certain waivers, Medicaid policy does not have separate eligibility categories or specific programs for these populations.

At the most aggregated level, about half (49 percent) of LTSS users were age 65 or over in FY 2010. Just over two in five (42 percent) were individuals under age 65 who qualified for Medicaid on the basis of a disability (Figure 2-3).

About half of Medicaid LTSS users were eligible as a result of having very low incomes, while the other half have comparatively higher incomes but qualified on the basis of also having significant LTSS needs (MACPAC 2014a).¹⁸

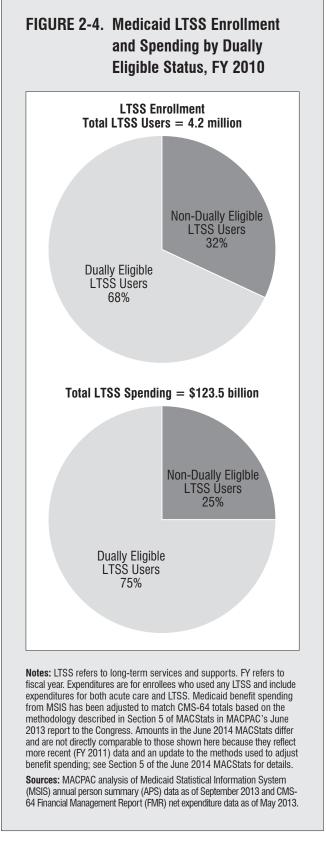
This latter group includes individuals who may have access to private health insurance, which does not typically cover LTSS (including such services as habilitation and respite for family caregivers), and who otherwise might face total impoverishment if they were to pay for services out of pocket. For these individuals, Medicaid acts as a wraparound to supplement private health insurance. For example, in 2010, about 8 percent of children with special health care needs had both private insurance and Medicaid.¹⁹ Other populations, including working adults with disabilities, may also rely on Medicaid to act as a wraparound to their private health insurance.



LTSS users by dually eligible status

Service use and total expenditures vary considerably across different subpopulations of LTSS users. Even so, it can be difficult to assess whether differences in use reflect differences in need or the design of coverage, eligibility, and costsharing policies.

The majority (68 percent) of Medicaid LTSS users are dually enrolled in Medicare and Medicaid (Figure 2-4). Medicaid pays for LTSS but not for most acute medical care for dually eligible enrollees, whereas it covers both acute care and LTSS for



non-dually eligible enrollees. It is important to note that not all persons dually enrolled in Medicaid and Medicare are disabled; almost two-thirds

Eligibili	ty Pathway, F	í 2010				
Dually Eligible Enrollees Who Use LTSS	Number of LTSS Users (thousands)		caid LTSS Sper er FYE LTSS Uso Institutional		Medicaid Non-LTSS (Acute and Other) Spending Per FYE LTSS User*	Total Medicaid Spending Per FYE LTSS User
Dually eligible LTSS u			Incircuitoriai			
Total	2,869	\$35,396	\$21,701	\$13,695	\$7,204	\$42,600
Benefit package			i i	· ·		
Full benefit Partial benefit Age	2,792 78	36,178 7,712	22,250 2,292	13,929 5,420	7,291 4,112	43,469 11,824
Children (< Age 21) Adults (Age 21–64) Individuals Age 65+ Medicaid eligibility pa	5 842 2,023 athway	34,544 41,565 32,628	14,554 16,919 23,868	19,990 24,647 8,760	22,133 9,009 6,352	56,677 50,575 38,980
SSI Poverty-related Medically needy Section 1115 waiver Special income level or other	917 271 432 5 1,244	23,697 22,950 56,133 18,936 40,599	5,035 13,145 44,788 14,092 29,152	18,662 9,805 11,345 4,844 11,446	8,909 6,622 7,397 14,605 5,873	32,606 29,571 63,530 33,541 46,472
Dually eligible LTSS u			tional			
Total	154	41,344	27,472	13,872	10,567	51,911
Dually eligible LTSS u Total Dually eligible LTSS u	1,138	54,330	54,330	-	6,383	60,712
Total	798	32,855	_	32,855	6,733	39,588
Dually eligible LTSS u Total			-	12,223	8,114	20,337

TABLE 2-4. Medicaid Spending for Dually Eligible LTSS Users, by Type of LTSS User, Age, and Eligibility Pathway, FY 2010

*Other spending may include Medicaid spending for acute care services not covered by Medicare (e.g., vision, dental) and Medicare cost sharing.

Notes: LTSS refers to long-term services and supports. FY refers to fiscal year. FYE refers to full-year equivalent. HCBS refers to home and community-based services. SSI refers to Supplemental Security Income. Nearly all dually eligible enrollees under the age of 65 qualify for Medicaid on the basis of a disability; numbers shown here include a small number of individuals (about 8,000 adults and 200 children) who are not eligible on the basis of a disability. Individuals age 65 and older are eligible for Medicaid on the basis of factors other than disability. Medicaid benefit spending from MSIS has been adjusted to match CMS-64 totals based on the methodology described in Section 5 of MACStats in MACPAC's June 2013 report to the Congress. Amounts in the June 2014 MACStats differ and are not directly comparable to those shown here because they reflect more recent (FY 2011) data and an update to the methods used to adjust benefit spending; see Section 5 of the June 2014 MACStats for details. **Sources:** MACPAC analysis of Medicaid Statistical Information System (MSIS) annual person summary (APS) data as of September 2013 and CMS-64 Financial Management Report (FMR) net expenditure data as of May 2013.

(62 percent) of persons dually enrolled in Medicaid and Medicare did not use Medicaid LTSS in FY 2010 (MACPAC 2014a).²⁰ Nonetheless, persons dually enrolled in Medicaid and Medicare account for three-quarters of Medicaid spending on LTSS (Figure 2-4). Almost all dually enrolled individuals in Medicare and Medicaid who used Medicaid LTSS qualified for full Medicaid benefits in their state, including coverage of LTSS (referred to as full-benefit enrollees).²¹

Individuals dually enrolled in Medicare and

Medicaid. Persons dually enrolled in Medicare and Medicaid who use LTSS are more likely to be over age 65, and these older individuals are more likely to use institutional services. About 2 million out of the 2.9 million dually enrolled individuals who used LTSS in FY 2010 were age 65 or over; the remainder were younger adults with disabilities (Table 2-4). Moreover, individuals age 65 and over who were dually enrolled in Medicare and Medicaid had spending of \$23,868 per FYE enrollee for their institutional LTSS, which was 73 percent of total Medicaid LTSS spending per enrollee for that group (\$32,628 per FYE enrollee).

By contrast, adults age 21 to 64 who were dually enrolled had higher per FYE enrollee spending on HCBS (\$24,647) than institutional LTSS (\$16,919). Compared to other age groups who used LTSS, the dually enrolled adults age 21 to 64 had the highest total LTSS spending per FYE enrollee at \$41,565 per enrollee (Table 2-4).

Among dually enrolled LTSS users, LTSS spending also differed by the types of services this population used. Those who only used institutional LTSS had the highest LTSS per enrollee spending, compared to dually eligible enrollees who used only HCBS or who used both institutional and HCBS in FY 2010 (Table 2-4).

Of those dually eligible enrollees who used only HCBS, there was a substantial difference in per enrollee spending between those who accessed HCBS through waivers (\$32,855 per FYE enrollee) compared to those who accessed such services through the state plan (\$12,223 per FYE enrollee) (Table 2-4). The types of HCBS that dually eligible enrollees may have been accessing through the state plan include home health services, personal care services, and other optional LTSS (Table 2-3).

Medicaid LTSS spending also varies as a function of the eligibility pathway through which dually eligible enrollees enter Medicaid. Those who entered through the medically needy pathway had the highest LTSS per enrollee spending at \$56,133 per FYE enrollee, followed by enrollees who entered through the special income level pathway (\$40,599 per FYE enrollee) (Table 2-4).

Non-dually enrolled LTSS users. Most nondually enrolled LTSS users (sometimes called Medicaid-only users) were adults between the ages of 21 and 64 years in FY 2010 (Table 2-5). Most of these adults qualified through a disability pathway. Thirty-eight percent, or around 528,000, of non-dually eligible enrollees who used LTSS were children under the age of 21. Among those children, over half (280,000 or 53 percent) qualified for Medicaid on a basis other than a disability (i.e., through a low-income family or Section 1115 waiver pathway) meaning that they accessed LTSS through EPSDT or other state plan benefits (Table 2-5). The LTSS used by children who came through a non-disability eligibility pathway may include such services as habilitative or rehabilitative care available through the state plan.

Spending patterns for non-dually eligible LTSS users differ by Medicaid eligibility pathway. Those who entered through the SSI-related or special income level eligibility pathways had higher per enrollee spending on HCBS than on institutional LTSS (Table 2-5). Those enrollees who entered through the other major disability-related pathways (i.e., poverty-related, medically needy, or Section 1115 waiver), in contrast, had more spending for institutional LTSS than for HCBS.

Over 1 million out of almost 1.4 million non-dually eligible enrollees who used LTSS used only HCBS (79 percent). Two-thirds (65 percent or 703,000) of non-dually eligible enrollees who used only HCBS accessed those services through the state plan (MACPAC 2014a). And those who used HCBS through waivers had much higher LTSS per enrollee spending, five times that of those who used only state plan HCBS (\$35,852 per FYE enrollee versus \$7,104 per enrollee, respectively) (Table 2-5).

Among non-dually eligible enrollees who used LTSS, per enrollee spending was roughly the same for acute care (\$27,306 per FYE enrollee) and LTSS (\$24,957 per FYE enrollee). However, variation in per FYE enrollee spending for acute care existed by the type of LTSS used. Enrollees who used both institutional and HCBS during FY 2010 had substantially higher per enrollee spending on acute care (\$65,993 per FYE enrollee) than other enrollees,

Eligibility Pathway, FY 2010										
Non-Dually Eligible	Number of LTSS Users		caid LTSS Spe er FYE LTSS Us	er	Medicaid Non-LTSS (Acute and Other) Spending Per FYE	Total Medicaid Spending Per				
Enrollees Who Use LTSS	(thousands)	Total	Institutional	HCBS	LTSS User*	FYE LTSS User				
Non-dually eligible LTSS use										
Total	1,373	\$24,957	\$10,340	\$14,617	\$27,306	\$52,263				
Age and disability status										
Children (< Age 21) eligible on the basis of a disability	248	26,300	6,991	19,309	29,683	55,984				
Children (< Age 21) eligible on a basis other than disability	280	8,359	5,410	2,949	16,775	25,134				
Adults (Age 21–64) elgible on the basis of a disability	687	32,605	13,385	19,220	30,705	63,310				
Adults (Age 21–64) eligible on a basis other than disability	88	3,511	1,627	1,884	27,093	30,605				
Individuals Age 65+	70	29,356	12,257	17,100	17,787	47,143				
Medicaid eligibility pathway		,	,	ŕ	,					
SSI	853	27,410	10,038	17,372	28,044	55,454				
Poverty-related	179	6,443	3,657	2,786	18,749	25,192				
Medically needy	82	34,921	25,419	9,503	38,873	73,795				
Section 1115 waiver	31	4,558	2,759	1,799	23,800	28,358				
Special income level or other	229	28,293	12,355	15,938	27,337	55,630				
Non-dually eligible LTSS use	rs: Both HCBS		utional							
Total	44	49,051	33,595	15,456	65,993	115,044				
Non-dually eligible LTSS use										
Total	243	55,262	55,262	-	32,298	87,560				
Non-dually eligible LTSS use										
Total	384	35,852	_	35,852	17,851	53,703				
Non-dually eligible LTSS use			1							
Total	703	7,104	-	7,104	28,650	35,754				

TABLE 2-5. Medicaid Spending for Non-Dually Eligible LTSS Users, by Type of LTSS User, Age, andEligibility Pathway, FY 2010

* Acute and other spending includes, hospital care, prescription drugs, ambulatory care, and all Medicaid non-LTSS expenditures, as well as capitation payments to managed care plans.

Notes: LTSS refers to long-term services and supports. FY refers to fiscal year. FYE refers to full-year equivalent. HCBS refers to home and community-based services. SSI refers to Supplemental Security Income. Individuals age 65 and older are eligible for Medicaid on the basis of factors other than disability. Medicaid benefit spending from MSIS has been adjusted to match CMS-64 totals based on the methodology described in Section 5 of MACStats in MACPAC's June 2013 report to the Congress. Amounts in the June 2014 MACStats differ and are not directly comparable to those shown here because they reflect more recent (FY 2011) data and an update to the methods used to adjust benefit spending; see Section 5 of the June 2014 MACStats for details.

Sources: MACPAC analysis of Medicaid Statistical Information System (MSIS) annual person summary (APS) data as of September 2013 and CMS-64 Financial Management Report (FMR) net expenditure data as of May 2013.

with the next highest acute care spending per FYE enrollee among those who used only institutional care (\$32,298 per FYE enrollee) (Table 2-5).

As previously mentioned, the fact that nondually enrolled LTSS users are more expensive to Medicaid than those individuals dually enrolled in Medicare and Medicaid reflects in part the fact that Medicare pays for most of the acute care services for individuals dually enrolled in Medicare and Medicaid. Even so, it is not clear to what extent other differences in spending and use reflect interactions between the Medicaid and Medicare programs versus the specific characteristics of the enrollees in each group.

LTSS users by disability-specific group

Examining LTSS utilization and spending by enrollees' specific disabilities, diagnoses, and

functional abilities can shed light on the different types of services that are important to different groups. These distinctions can be useful in thinking about how policies might be changed to promote efficiency, quality, and access. This is because enrollees with specific disabilities may require similar LTSS; for example, enrollees with cognitive limitations are likely to have different LTSS needs than enrollees with profound physical functional limitations or enrollees with serious mental illness.

As mentioned previously, Medicaid's current role in providing LTSS to these subpopulations is in part a vestige of now defunct state programs. Over time, Medicaid policy has allowed states to develop HCBS waivers to target certain groups. Federal regulations implementing HCBS programs-specifically, Section 1915(c) and Section 1915(i) of the Act-require states to specify which subpopulations will be served by HCBS programs (CMS 2014a).²² Spending by these groups, therefore, is in part reflective of historical state policies as opposed to deliberate decisions about what might be most appropriate for different LTSS users and their specific disabilities. Prior to the enactment of Medicaid, most of these individuals were cared for in institutions, including nursing facilities, institutions for individuals with developmental disabilities, and long-stay hospitals, including psychiatric hospitals. Medicaid has evolved to replace categorical programs serving them or to target services to their specific needs. Today, states may cover specific Medicaid LTSS benefits that target certain subpopulations independent of age. These subpopulations are:

- enrollees with intellectual and developmental disabilities who require ICF/ID level of services;
- enrollees with disabilities (and those over age
 65) who qualify for nursing facility services;

- enrollees with serious mental illness who meet the level of care for inpatient psychiatric facilities; and
- enrollees with a disability or condition (such as brain injury) that requires the level of care provided in a hospital or who are otherwise medically frail.

Examples of services provided to major disability groups, using the patchwork of available data, are described here (Box 2-1). Analysis of Medicaid administrative data by disability-specific group was not available for this report; other data sources are used to illustrate key points related to each group.²³

Individuals with intellectual or developmental disabilities (ID/DD). The majority of LTSS spending for individuals with ID/DD is for HCBS. Forty-seven states spent at least 50 percent of their Medicaid LTSS expenditures that targeted individuals with ID/DD on HCBS in FY 2012, primarily on services through HCBS waivers (Eiken et al. 2014). Enrollees in ID/DD waiver programs accounted for 40 percent of total HCBS waiver participants and 71 percent of all spending on HCBS waivers (KCMU 2014a).

The average per enrollee expenditure for an individual with ID/DD in HCBS waivers is among the highest of all users of LTSS waiver services (Table 2-6). These high expenses are in part because people with ID/DD use more in-home and outof-home residential support that is frequently round-the-clock (Rizzolo et al. 2013). A study of 88 HCBS waivers found that over half (53 percent) of spending for individuals with ID/DD was for residential habilitation services, which can include such services as "assistance with activities of daily living, community inclusion, transportation, adult educational supports, social and leisure skill development, that assist the participant to reside in the most integrated setting appropriate to his/her needs" (Rizzolo et al. 2013). LTSS facility services

BOX 2-1. Illustrative Examples of Medicaid Benefits for Selected Subpopulations

Services for people age 65 and older and people with disabilities

- In State A, adults who are over age 65 or who have physical disabilities that require nursing care can receive long-term services and supports (LTSS) in the community or nursing facilities if they are eligible for Supplemental Security Income (SSI). Individuals who earn too much for SSI can obtain Medicaid home and community-based services (HCBS) by paying a premium and other cost sharing, or they can enter a waiting list for HCBS services. Individuals who earn too much for SSI can obtain Medicaid LTSS in nursing facilities.
- In State B, adults over age 65 and who require a nursing facility level of care may receive HCBS if their monthly income does not exceed \$903, they pay a premium or the costs of some of their care, or they enroll in the Medicaid waiver, which has a small waiting list.

Services for people with ID/DD

- In State A, adults with intellectual or developmental disabilities (ID/DD) who do not qualify for SSI, either because they earn too much or because they do not meet the functional definition, can receive services in an intermediate care facility for persons with intellectual disabilities (ICF/ID), or they can enter a waiting list for HCBS.
- In State B, adults with ID/DD who do not otherwise qualify for SSI will still receive Medicaid LTSS. There is no waiting list for services, although individuals seeking out-of-home residential services (such as group homes) may wait for these services based on the prioritization of their needs.

Services for individuals with SMI

- An individual with severe mental illness (SMI) who is eligible for SSI can receive partial hospitalization, habilitation, and adult day health services in State A. If they earn more than \$721 per month, however, they will not receive Medicaid unless they pay a premium and other cost sharing.
- In State B, an individual with a severe, disabling mental illness (SDMI) may receive day habilitation, prevocational services, private duty nursing, homemaker and chore services, case management, and many other services under the HCBS waiver for individuals with SDMI. Only 155 individuals are served in this program and to receive these services, the individual must: qualify for SSI (or earn no more than \$721/month in 2014), require a nursing facility level of care, and reside in one of the 21 counties served by the waiver.

Services for individuals who are medically frail

- State A operates an HCBS waiver that provides attendant care and other services to individuals with traumatic brain or spinal cord injury (TBI/SCI). Individuals with TBI/SCI who receive SSI do not have access to attendant care services unless they enroll in the waiver, which has a waiting list. Individuals with TBI/SCI who earn up to 300 percent of SSI may also enroll in the waiver, but individuals who have an acquired brain injury (such as one resulting from a stroke) are not eligible.
- An individual with any type of brain injury cannot get private duty nursing or personal care services in State B unless they enroll in the HCBS waiver whether or not they qualify for SSI. If their incomes are less than 300 percent of SSI, they will remain eligible for the waiver.

Notes: These examples are provided as an illustration of the variation in Medicaid LTSS across and within states. Individual circumstances and specific state policies determine whether an individual is eligible for Medicaid and what LTSS they may receive. Appendix Table 2-A-4 lists LTSS benefits by state.

by Subpopu	lation, FY 2010		
	Total U.S. Waiver Expenditures (thousands)	Total Waiver Enrollment	Per Enrollee Spending
Total	\$36,803,080	1,403,736	\$26,218
ID/DD	26,175,736	567,117	46,156
Aged	1,752,171	168,966	10,370
Aged and disabled	5,984,075	512,480	11,677
Physically disabled	1,743,076	85,537	20,378
Children	423,230	36,270	11,669
HIV/AIDS	51,904	12,930	4,014
SMI	41,711	3,243	12,862
TBI/SCI	631,177	17,193	36,711

TABLE 2-6. Section 1915(c) Home and Community-Based Services Waiver Enrollment and Spending by Subpopulation, FY 2010

Notes: FY refers to fiscal year. Aged includes waivers targeting individuals age 65 and older. Aged and disabled includes waivers targeting both individuals age 65 and older and those with physical disabilities. Physically disabled includes waivers targeting individuals with physical disabilities. ID/DD refers to individuals with intellectual or developmental disabilities and includes waivers targeting this population. TBI/SCI refers to individuals with traumatic brain injury or spinal cord injury and includes waivers targeting this population. SMI refers to individuals with severe mental illness and includes waivers targeting this population. **Source:** KCMU 2014a.

that provide round-the-clock residential support (such as ICFs/ID) also have higher per-person annual expenditures than other LTSS facilities (such as nursing facilities) (Eiken et al. 2014).

Individuals age 65 and older or individuals with physical disabilities. Individuals age 65 and older and individuals under age 65 with physical disabilities have lower expenditures on average than other LTSS users, despite the fact that individuals age 65 and older have higher institutional utilization rates (Eiken et al. 2014). They comprise the largest share of participants (49 percent) in HCBS waiver programs (Table 2-6) (KCMU 2014a). Per enrollee expenditures for this group in HCBS waivers are generally less than expenditures for ID/DD waivers but greater than those for persons in waivers serving individuals with mental illness (Table 2-6).

Individuals with serious mental illness (SMI). Individuals with SMI represent another substantial share of individuals who use LTSS. Adults with SMI represented over a third (37 percent) of SSI recipients nationwide; about 42 percent of all LTSS users enter through the SSI pathway (described previously) (SSA 2012).²⁴

The population with SMI tends to use LTSS differently than other disability-specific groups. Whereas other LTSS users have needs that are relatively consistent over time, those with SMI may have episodic periods of need that would qualify them for LTSS combined with periods of relatively low functional impairment. In these periods of improvement, individuals with SMI may no longer qualify for services restricted to enrollees with severe disabilities, although providing continued services can prevent acute exacerbation of symptoms (ASPE 1995).

Persons with SMI account for an extremely small share of enrollment (0.2 percent) among HCBS waiver programs (Table 2-6). This may reflect the fact that states are not permitted to use Medicaid funds to operate institutions for the working age population with SMI (§1905(a)(29)(B)). Given the lack of Medicaid support for institutional care, states considering a Section 1915(c) HCBS waiver targeting adults with SMI often find it difficult to make the case that costs will be the same under HCBS (Shirk 2006).²⁵ States may therefore serve individuals with SMI by tailoring certain optional state plan services, such as rehabilitation or Section 1915(i) state plan HCBS.²⁶ Despite their relatively small enrollment in Section 1915(c) waiver programs, individuals with SMI have high per capita total Medicaid expenditures, which may include non-waiver LTSS (such as rehabilitation) and other acute services (GAO 2014).

Individuals who are medically frail or have hospital level-of-care needs. States have developed Section 1915(c) HCBS waiver programs to provide services to individuals who meet hospital level-of-care criteria and who are medically frail and have complex health needs. These may focus on individuals with conditions such as HIV/ AIDS who require intensive, long-term medical care to maintain their functioning and quality of life and children who are medically complex and may have high medical expenses related to equipment and aids they need on a daily basis. Of those states that have developed waivers for these populations, 23 have targeted individuals with brain injury and 13 have targeted individuals with HIV/ AIDS. Individuals with traumatic brain injury or spinal cord injury (TBI/SCI) made up 1 percent of HCBS waiver enrollment in FY 2010, and individuals with HIV/AIDS made up 0.9 percent (Table 2-6). Similar to individuals with SMI, total Medicaid expenditures for individuals with HIV/ AIDS are substantial and may indicate use of other Medicaid services in addition to LTSS (GAO 2014).

Looking Ahead

LTSS are now provided to Medicaid enrollees who need them through a patchwork of services and eligibility policies that differ by state, enrollee group, statutory authority, and other factors. Policy has evolved over time such that the pieces do not fit together in a way that seems rational, efficient, or best suited to the needs of enrollees with varying needs for support. Moreover, coordination with other state agencies that provide LTSS or other services that affect the provision of Medicaid LTSS complicates the task of reform.

The flexibility given to states has had its advantages. Waiver and demonstration programs, and flexibility in service design and payment methods have allowed states to innovate with providing LTSS to targeted groups of enrollees and to test new models. On the other hand, the broad array of programs and the lack of standardization in eligibility, functional assessment, payment methodologies, and quality measures make it difficult to determine what program features are most worthy of replication.

Federal policy could be changed to standardize eligibility pathways and LTSS benefits to begin addressing some of the issues around state variation in covering LTSS, but this would provide states with less control over program budgets and less ability to tailor benefits and program design to target resources where they are most needed. Moreover, the extent to which such variation contributes to inequitable and inefficient service utilization is not clear. Because there are few standard metrics of service use, outcomes, payment methods, or quality, comparison of outcomes and costs is difficult to make. Without these metrics, it is difficult for policymakers to understand how federal dollars are being spent and whether certain policies should be incentivized or discouraged.

From the beneficiary's perspective, different eligibility criteria across different LTSS programs may be confusing, allow individuals with similar functional limitations to receive different services, and affect access. Enrollees using Medicaid LTSS are often enrolled in both Medicaid and state-only funded programs. They may have to communicate with multiple, uncoordinated entities, which can lead to delayed eligibility determinations, impeded access to services, and even unnecessary institutionalization.

Several other issues also complicate the task of designing a more rational and efficient system of LTSS.

First, decisions about how much and what type of assistance federal and state governments should provide are part of a broader unresolved conversation about the appropriate roles of individuals in planning for potential long-term care needs, family participation in caregiving, and the notion of independence and engagement for the individual. Not all families have the financial resources or skills to provide the care their loved ones need. And for some, leaving family caregivers for independent life in the community is consistent with autonomy and community engagement. Moreover, needs for LTSS are highly individualized. What might be sufficient support for one person might not work for another.

Second, the movement to keep individuals out of institutional settings assumes that people with LTSS needs have appropriate housing. While Medicaid can pay for individuals to reside in institutional and group home settings, the restriction makes it more difficult to keep people in the community when enrollees do not have the ability to pay for housing or housing modifications needed to accommodate their functional limitations, regardless of the other HCBS services Medicaid can provide.

Third, interactions between Medicaid LTSS and other payers create an additional set of challenges for policymakers to consider. As previously mentioned, over two-thirds of Medicaid enrollees who use LTSS are also covered by Medicare. Therefore, policy makers should consider how changes made to Medicare coverage of services affect Medicaid LTSS for this population. For example, CMS is testing new delivery systems for dually eligible enrollees through the Financial Alignment Initiative demonstrations, including how and where they receive LTSS. The recent court decision in *Jimmo v. Sebelius* that addressed Medicare coverage of skilled care services also raises questions around the interaction of Medicare and Medicaid in providing such services to those dually enrolled in both programs.

Changes in service delivery among payers in addition to Medicare may also directly affect how Medicaid covers LTSS for its enrollees. For individuals with private coverage, which services including LTSS such as therapies, respite care or personal care—health plans choose to cover will also be a factor in how these LTSS can be provided to individuals in need.

Next Steps

Keeping in mind the complicated issues related to Medicaid LTSS, MACPAC has identified several areas where it could contribute to building understanding and moving policy in the direction of a more efficient and effective system of LTSS. These include examining the design and policy issues associated with the movement to managed long-term services and supports (MLTSS), studying the use of HCBS waivers, assessing the merits of moving to standardized functional assessments for Medicaid LTSS, and analyzing how to improve data on LTSS to support policy analysis, evaluation, and future program design.

Managed long-term services and supports (MLTSS)

The number of states with MLTSS programs doubled from 8 to 16 between 2004 and 2012, and the number of persons receiving LTSS through managed care programs increased from 105,000 to 389,000. The number of states projected to have MLTSS programs by 2014 is 26 (Saucier, et al. 2012). MLTSS programs differ in terms of populations and services covered, the types of organizations managing services, and the level of integration with other types of services.

MLTSS models are still developing, and there is limited systematic information across states about how well they perform on cost and quality metrics. However, there are recent efforts to address these concerns. For example, many states that are participating in the Financial Alignment Initiative are testing the capitated model, which requires managed care plans participating in the states' demonstrations to be at risk for LTSS for individuals dually enrolled in Medicare and Medicaid. The evaluations and outcomes that result from the Financial Alignment demonstrations will affect enrollees who receive LTSS. Although these demonstrations focus on people dually enrolled in Medicare and Medicaid, many of the state demonstrations have policies and protections that can inform how to best deliver MLTSS to all Medicaid enrollees who use LTSS.

In the year ahead, MACPAC will be conducting indepth site visits to five states that have implemented managed care delivery of LTSS. This study is designed to address questions on how programs operate; what roles and responsibilities are delegated to different entities and how these activities are managed; how oversight and enforcement of the MLTSS contractor is conducted and by whom; what is known about the differences in cost, service utilization, level of integration across LTSS and other health care services including acute care and pharmacy, provider participation, and beneficiary satisfaction; and other issues. We will continue to track the growth and maturation of MLTSS and emerging information on how these arrangements affect access to care and expenditures.

HCBS waivers

Although HCBS waivers have proliferated, the significant variation in eligibility requirements and benefits makes it difficult to compare programs across states and populations. MACPAC will take a deeper look at the use of waivers and strategies to increase the efficiency of delivering HCBS. We plan to explore states' use of HCBS waivers, recent changes to reduce administrative burden, and any further steps that might be taken to respond to states' concerns around waiver complexity. The use of waiting lists for HCBS waivers also requires further exploration, including to what extent the waiver programs meet need and demand, different strategies states use to prioritize access to HCBS, and ways in which data can be improved to better document and describe the size and scope of unmet need for HCBS.

In the same regard, a better understanding of how service utilization of both acute and LTSS is affected for enrollees who must wait for services may help identify potential areas that can be improved. MACPAC will consider ways to balance states' desires to target programs to their specific populations with CMS' responsibility to oversee the programs by using reporting requirements that are effective and efficient.

Standardizing eligibility assessments

Medicaid LTSS may be improved in some ways by better matching LTSS to enrollee needs. Implementing standardized assessments has been identified as a potential strategy to achieve this result, and several states are in the process of doing so either independently or as a result of their participation in the BIP, which requires participating states to institute a core standardized assessment. As standardization increases, however, individualization may decrease and this may be at odds with efforts to develop person-centered services.

Additionally, standardized eligibility assessments and prestructured care plans may not capture information on individual circumstances and support and acute care needs that are integral to achieving optimal outcomes for the enrollee. The omission of an enrollee's individual support needs when subsequently developing the plan of care for that individual may lead to inappropriate allocation of services and supports.

MACPAC will monitor trends in standardization of functional eligibility assessments across states and programs. We hope to learn more about the relationship of these standardized measures to utilization, expenditures, and, ideally, outcomes. Further examination of states that have developed more advanced standardized assessment systems as well as those states participating in the BIP may provide useful insights on how to create a more streamlined and equitable assessment system for determining eligibility for Medicaid LTSS.

Data

Much of the information sought about Medicaid LTSS users-the types of services they need and use, the goals of service plans and expected outcomes, where they receive care, and payments at the service level-are not discernible from current data sources. For example, there is no federal data source that allows policymakers to compare HCBS utilization and expenditures across states and programs. This knowledge gap makes it difficult to develop effective policy solutions, although much can be learned from states' experiences operating HCBS programs. However, CMS has developed methods by which Medicaid administrative data can be analyzed by different disabling conditions and can further refine expenditures into more specific categories of LTSS (such as specific types of HCBS) (CMS 2013, Peebles and Bohl 2013).

Two areas appear to be promising avenues for MACPAC to pursue. First the Commission could monitor incorporation of the new HCBS taxonomy (a uniform classification system for HCBS) into the Transformed Medicaid Statistical Information System (T-MSIS) to integrate standardized definitions of HCBS; the Commission could then consider how such data might be used to compare and evaluate HCBS across states and programs and also to link provision of HCBS with clinical outcomes when possible.27 On issues related to payment and financing, MACPAC will also document payment methodologies used by states to pay for LTSS and to set capitation rates that include LTSS, and investigate the adequacy of LTSS financing.

Endnotes

¹ Katie A. v. Douglas, CV-02-05662 AHM (SHX) (C.D. Cal. 2011) (Formerly Katie A. v. Bonta) and T.R. et al. v. Kevin Quigley and Dorothy Teeter, C09-1677 – TSZ (W.D. Wash. 2013) (Formerly T.R. et al. v. Kevin Quigley and Dorothy Teeter, C09-1677-JPD).

² *Moore v. Reese*, 637 F.3d 1220, 1224-29 (11th Circuit Court of Appeals 2011).

³ On January 24, 2013, the U.S. District Court for the District of Vermont approved a settlement agreement in the case of *Jimmo v. Sebelius* that required the Centers for Medicare & Medicaid Services (CMS) to clarify that Medicare beneficiaries who required a covered level of skilled care could not be denied services if their health would not be restored or improved. Federal regulations specify that the restoration of a patient is not the deciding factor in determining whether skilled services are needed and even if full recovery or medical improvement is not possible, a beneficiary may still need (and receive) skilled services to prevent further deterioration or preserve current capabilities.

⁴ Level-of-care (LOC) criteria may be based on specific diagnoses or conditions; on functional status as measured by activities of daily living (ADLs) such as bathing, dressing, or eating; on enrollees' functional performance measured by instrumental activities of daily living (IADLs) such as shopping, money management, or medication management; on other functional skills such as adaptive behaviors; or on other criteria. States may also examine an individual's cognitive, behavioral, or other impairments; medical or nursing needs; presence of informal supports; and functional limitations related to ability to perform ADLs and IADLs or major life activities. Some states have established a high threshold for the LOC criteria used to determine LTSS eligibility-such as requiring an individual to be dependent in four or more ADLs-while other states may require dependency in two ADLs. Most states also use a combination of specific diagnosis and some functionally based level of care for assessment purposes for both determining LOC eligibility for nursing facilities and intermediate care facilities for individuals with intellectual and developmental disabilities (ICFs/ID) as well as home and community-based services (HCBS) waiver programs (Hendrickson 2008, Zaharia 2008).

⁵ Federal statute allows states to serve individuals with LTSS needs who have higher levels of income than other Medicaid enrollees (e.g., individuals who come through the special income level pathway (§1902(a)(10)(A)(ii)(V) of the Act)).

⁶ The 209(b) states are: Connecticut, Hawaii, Illinois, Minnesota, Missouri, New Hampshire, North Dakota, Ohio, Oklahoma, and Virginia. These states have more restrictive financial and non-financial (e.g., definition of disability) criteria than SSI. However, these criteria may not be more restrictive than those in effect on January 1, 1972.

⁷ Thirty-three states and the District of Columbia request the Social Security Administration (SSA) to make Medicaid eligibility determinations, under a 1634 agreement. Alaska, Idaho, Kansas, Nebraska, Nevada, Commonwealth of the Northern Mariana Islands, Oregon, and Utah make their own Medicaid determinations using SSA criteria.

⁸ In FY 2014, the federal poverty level (100 percent FPL) is \$11,670 for an individual and \$4,060 for each additional family member in the lower 48 states and the District of Columbia.

⁹ In FY 2010, 35 percent of LTSS users were eligible under the special income level or one of the other optional eligibility pathways such as Katie Beckett. Although a future version of the data source used to calculate this statistic (the federal Medicaid Statistical Information System) will collect additional detail on the eligibility categories under which individuals enroll in Medicaid, it is not currently possible to determine how many of this group were eligible under the special income level.

¹⁰ As of November 2013, California had submitted three Section 1915(i) state plan amendments (one has been approved); North Carolina had submitted two Section 1915(i) state plan amendments.

¹¹ Federal statute prohibits individuals from transferring assets to another individual or transferring an asset into an irrevocable trust in the five years prior to applying for Medicaid (§1917(c) of the Act).

¹² Nursing home residents and residents of ICFs/ID may retain a monthly personal needs allowance (PNA) that can be used by the beneficiary to pay for goods and services not provided by the facility or covered by Medicaid (the facility payment covers room and board of the beneficiary). In 2009, PNA amounts ranged from \$30 to \$100 per month (Stone 2011). Medicaid beneficiaries in HCBS waiver programs are allowed a monthly maintenance needs allowance (MMNA), the amount of which is what an HCBS waiver participant may retain for living expenses. States that offer eligibility to individuals under the special income level pathway may also set an unlimited MMNA, so long as any income above the special income level (e.g., any amounts above 300 percent SSI) is placed in a Miller Trust (§1902(a)(10)(A)(ii)(V) and §1917(d) of the Act). ¹³ The statutory authority waived under Section 1115 and Section 1915(c) of the Act may vary considerably across states and individual waiver requests. Under Section 1115 CMS may grant waivers as necessary to carry out an experimental, pilot or demonstration project likely to assist in promoting the objectives of the Medicaid program. Section 1915(c) provides states the option to modify their Medicaid programs to implement specific statutorily defined program options (e.g., home and community-based services). The application and approval processes also vary for Section 1115 and Section 1915(c) waiver requests.

¹⁴ States often have more individuals requesting Section 1915(c) waiver services than the enrollment limit or program budget can accommodate. As a result, states may maintain waiting lists for these waivers.

¹⁵ CMS requires states to renew Section 1115 waivers every three years and Section 1915(c) waivers every five years after the initial three-year approval.

¹⁶ Delaware, Hawaii, New York, Tennessee, and Texas provide LTSS to various populations under both Section 1115 and Section 1915(c) authority.

¹⁷ Housing costs include real estate costs (such as rent, furnishings, utilities, maintenance, etc.) and food costs (separate from the cost of meal preparation services provided by staff).

¹⁸ Policies—such as spousal impoverishment, institutional deeming rules, income disregards, and special needs trusts—eliminate the upper income limits for receipt of Medicaid LTSS, allowing individuals who would otherwise not qualify due to income or assets to access Medicaid LTSS. States may also require individuals to contribute to the costs of their care above any established personal needs or monthly maintenance needs allowances retained by the individual and via estate recovery programs after their deaths.

¹⁹ MACPAC analysis of the National Survey of Children's Health, online tabulations available from http://www.childhealthdata.org/browse/survey?s=2.

²⁰ A recent databook on dually eligible enrollees provides a more complete picture of spending on this population, including both Medicaid and Medicare spending (MACPAC and MedPAC 2013).

²¹ The remaining share of Medicaid LTSS users who are dually enrolled in Medicaid and Medicare include individuals who received Medicaid assistance only with Medicare cost sharing for services provided in the Medicare program (referred to as partial-benefit dually eligible enrollees). See Chapter 4 in MACPAC's March 2013 report to the Congress for further information. ²² States must designate target population groups for a single Section 1915(c) waiver or Section 1915(i) state plan amendment. The target population groups may include any of the three primary populations (individuals with intellectual or developmental disabilities, individuals with disabilities, or individuals who are over age 65), a subpopulation of these groups (e.g., individuals with mental illness), or any combination of groups (CMS 2014a).

²³ Sources of Medicaid administrative data are primarily designed to pay claims rather than to facilitate analysis of populations by their diagnosis or the functional impairment that was the original basis for an individual's disability determination. In order to determine the different types of disabilities and conditions that individuals with longterm care needs have, alternative data sources—such as the Social Security Administration data and HCBS waiver enrollment information—are often used. LTSS expenditures by condition subgroups is obtainable but has not been widely analyzed, and current data sources are limited in their ability to capture data on groups being served in managed care programs.

²⁴ According to SSA data, a mental disorder includes, for example, schizophrenia, bipolar disorder, psychosis, or depression. HCBS waivers may target individuals with mental illness that creates a need for institutional level of care, irrespective of diagnosis.

²⁵ To be approved by CMS, average per capita costs of a Section 1915(c) HCBS waiver program must not exceed what the average per capita institutional costs would have been under the state plan if the waiver had not been in operation (CMS 2008). Because state plan services do not include institutional services for adults age 18–64 with serious mental illness (institutes for mental disease), states may not have any institutional costs for this population.

²⁶ In 2007, 47 states provided some type of mental health services under rehabilitation state plan services, and in 2004, 73 percent of enrollees receiving these services had mental illnesses (KCMU 2007).

²⁷ CMS developed the HCBS taxonomy to create a common language for describing and categorizing HCBS (Peebles and Bohl 2013). See MACPAC's June 2013 report to the Congress on CMS' efforts to improve Medicaid data issues.

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Chapter 2 Appendix

APPENDIX TABLE 2-A-1. Individuals with Developmental Disabilities: Shared Responsibility among Medicaid and Other State Entities in Providing Medicaid LTSS by State, 2013

Stata	Part of the Same Agency	Reports to Medicaid	Logation If Not under Mediacid Director
State	as Medicaid? No	Director?	Location If Not under Medicaid Director
Alabama	Yes	No	Division of Developmental Disabilities, Department of Mental Health
Alaska		Yes	N/a Division of Developmental Dischility Convises Department of Economic Convits
Arizona	No	No	Division of Developmental Disability Services, Department of Economic Security
Arkansas	Yes	No	Division of Developmental Disabilities Services, Department of Human Services
California	No	No	Department of Developmental Services
Colorado	Yes	Yes	n/a
Connecticut	No	No	Department of Developmental Services
Delaware	Yes	No	Division of Developmental Disabilities Services, Delaware Health and Social Services
District of Columbia	Yes	Yes ¹	n/a
Florida	No	No	Agency for Persons with Disabilities
Georgia	Yes	Yes	n/a
Hawaii	Yes	Yes ²	n/a
Idaho	Yes	Yes ³	n/a
Illinois	No	No	Department of Human Services
Indiana	No	No	Division of Disability and Rehabilitative Services, Family and Social Services Administration
lowa	Yes	No	Division of Mental Health and Disability Services, Department of Human Services
Kansas	No	No	Department of Aging and Disability Services
Kentucky	No	No	Developmental and Intellectual Disabilities, Department of Behavioral Health
Louisiana	Yes	No	Office for Citizens with Developmental Disabilities, Department of Health and Hospitals
Maine	Yes	No	Office of Aging and Disability Services, Department of Health and Human Services
Maryland	Yes	No	Developmental Disabilities Administration, Department of Health and Mental Hygiene
	Yes	No	
Massachusetts			Department of Developmental Services
Michigan	Yes	No	Developmental Disability Administration, Department of Mental Health
Minnesota	Yes	No	Disability Services Division, Department of Human Services
Mississippi	No	No	Department of Mental Health
Missouri	No	No	Department of Mental Health
Montana	Yes	Yes	n/a
Nebraska	Yes	No	Division of Developmental Disabilities, Department of Health and Human Services
Nevada	Yes	No	Division of Public and Behavioral Health, Department of Health and Human Services
New Hampshire	Yes	No	Bureau of Developmental Services, Department of Health and Human Services
New Jersey	Yes	No	Division of Developmental Disabilities, Department of Human Services
New Mexico	No	No	Developmental Disabilities Services Division, Department of Health
New York	No	No	Office for People with Developmental Disabilities
North Carolina	Yes	No	n/a
North Dakota	Yes	No	Developmental Disabilities Division, Department of Human Services
Ohio	No	No	Department of Developmental Disabilities
Oklahoma	No	No	Department of Human Services
Oregon	No	No	Department of Human Services
Pennsylvania	Yes	No	Office of Developmental Programs, Department of Public Welfare
Rhode Island	No	No	Developmental Disabilities and Hospitals, Department of Behavioral Healthcare
South Carolina	Yes	Yes ⁴	n/a
South Dakota	No	No	Department of Human Services
Tennessee	No	No	Department of Intellectual and Developmental Disabilities
_	Yes	NO	Department of Aging and Disability Carvines
Texas			Department of Aging and Disability Services
Utah	No	No	Department of Human Services
Vermont	Yes	No	Division of Disability and Aging Services, Department of Disabilities, Aging & Independent Living
Virginia	Yes	No	Department of Behavioral Health and Developmental Services
Washington	No	No	Developmental Disabilities Administration, Department of Social and Health Services
West Virginia	No	No	Bureau of Behavioral Health and Health Facilities Department of Health & Human Resources
Wisconsin	Yes	No	Division of Long Term Care, Department of Health Services
	Yes	No	Repayioral Health Division Department of Health
Wyoming	res	110	Behavioral Health Division, Department of Health

Notes: LTSS refers to long-term services and supports. HCBS refers to home and community-based services.

1 Developmental Disabilities Administration of the Department of Disability Services is the operating agency for the HCBS waiver program, and the Department of Health Care Finance is the administrative agency.

2 To receive services, an individual must be referred by a case manager from the Developmental Disabilities Division of the Department of Health.

3 Idaho Medicaid shares responsibilities with Family and Children Services (FACS) and the Department of Health and Welfare. FACS administers case management for the children's developmental disabilities waiver. An independent contractor also plays a role in determining level-of-care eligibility for waiver services.

4 Department of Health and Human Services partners with the Department of Disabilities and Special Needs to serve individuals with developmental disabilities.

Source: State website search, 2013.

APPENDIX TABLE 2-A-2. Individuals Age 65 and Older and Individuals Physically Disabled: Shared Responsibility among Medicaid and Other State Entities in Providing Medicaid LTSS by State, 2013

State	Part of the Same Agency as Medicaid?	Reports to Medicaid Director?	Location If Not under Medicaid Director
Alabama	No	No	Departments of Senior Services and Rehabilitation Services
Alaska	Yes	Yes	n/a
Arizona	Yes	Yes	n/a
Arkansas	Yes	Yes	n/a
California	Yes	Yes	n/a
Colorado	Yes	Yes	n/a
Connecticut	Yes	Yes	n/a
Delaware	Yes	Yes	n/a
District of Columbia	Yes	Yes	n/a
Florida	Yes	Yes	
	Yes	Yes	n/a
Georgia			n/a
Hawaii	Yes	Yes	n/a
Idaho	Yes	Yes	n/a
Illinois	Yes	Yes	N/a Division of Asian Family and Casial Convises Administration
Indiana	No	No	Division of Aging, Family and Social Services Administration
lowa	Yes	Yes	n/a Department of Asian and Dischillty Convision
Kansas	Yes	No	Department of Aging and Disability Services
Kentucky	Yes	Yes	n/a
Louisiana	Yes	No	Office of Aging and Adult Services, Department of Health and Hospitals
Maine	Yes	Yes	n/a
Maryland	Yes	No	Maryland Department of Aging
Massachusetts	Yes	Yes	n/a
Michigan	Yes	Yes	n/a
Minnesota	Yes	No	Aging and Adult Services Division, Department of Human Services
Mississippi	Yes	Yes	n/a
Missouri	No	No	Department of Health and Senior Services
Montana	Yes	No	Senior and Long Term Care Division, Department of Public Health and Human Service
Nebraska	Yes	Yes	n/a
Nevada	Yes	No	Division of Aging and Disability Services, Department of Health and Human Service
New Hampshire	Yes	No	Bureau of Elderly and Adult Services, Department of Health and Human Services
New Jersey	Yes	No	Division of Aging Services, Department of Human Services
New Mexico	Yes	Yes	n/a
New York	Yes	Yes	n/a
North Carolina	Yes	Yes	n/a
North Dakota	Yes	Yes	n/a
Ohio	Yes	Yes	n/a
Oklahoma	Yes	No	Long Term Care Services Division, Department of Human Services
Oregon	No	No	Department of Human Services
Pennsylvania	Yes	No	Office of Long Term Living, Department of Public Welfare
Rhode Island	Yes	No	Long Term Care Office, Department of Human Services
South Carolina	Yes	Yes	n/a
South Dakota	Yes	No	Division of Adult Services and Aging, Department of Social Services
Tennessee	Yes	Yes	n/a
Texas	Yes	No	Department of Aging and Disability Services
Utah	Yes	Yes	n/a
Vermont	Yes	No	Aging and Independent Living, Department of Disabilities
Virginia	Yes	Yes	n/a
Washington	No	No	Aging & Disability Services Administration, Department of Social & Health Services
West Virginia	Yes	Yes	n/a
Wisconsin	Yes	No	Division of Long Term Care, Department of Health Services
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Note: LTSS refers to long-term services and supports. **Source:** State website search, 2013.

APPENDIX TABLE 2-A-3. Individuals with Serious Mental Illness: Shared Responsibility among Medicaid and Other State Entities in Providing Medicaid LTSS by State, 2013

State	Part of the Same Agency as Medicaid?	Reports to Medicaid Director?	Location If Not under Medicaid Director
Alabama	Yes	Yes	n/a
Alaska	Yes	Yes	n/a
Arizona	No	No	Division of Behavioral Health Services, Department of Health Services
Arkansas	Yes	Yes	n/a
California	Yes	Yes	n/a
Colorado	Yes	Yes	n/a
Connecticut	No	No	Connecticut Behavioral Health Partnership
Delaware	Yes	Yes	n/a
District of Columbia		Yes	n/a
Florida	Yes	Yes	n/a
Georgia	Yes	Yes	n/a
Hawaii	Yes	Yes ¹	n/a
Idaho	Yes	Yes	n/a
Illinois	Yes	Yes	n/a
Indiana	Yes	Yes	n/a Di isisa af Mastal I Iaulti and Diast illa Qualiana. Danatarata f I Iaura Qualiana
lowa	Yes	No Vac ²	Division of Mental Health and Disability Services, Department of Human Services
Kansas	Yes	Yes ²	n/a
Kentucky	Yes	Yes	n/a Office of Debautional Health Department of Health and Health is
Louisiana Maine	Yes Yes	No No	Office of Behavioral Health, Department of Health and Hospitals Office of Substance Abuse and Mental Health Services, Department of Health and Human Services
Maryland	Yes	No	Office of Behavioral Health and Disabilities, Department of Health and Mental Hygiene
Massachusetts	Yes	Yes	n/a
Michigan	Yes	No	Behavioral Health and Developmental Disabilities Administration, Department of Community Health
Minnesota	Yes	No	Mental Health Services Division, Department of Human Services
Mississippi	Yes	Yes	n/a
Missouri	Yes	Yes	n/a
Montana	Yes	Yes	n/a
Nebraska	Yes	No	Division of Behavioral Health, Department of Health and Human Services
Nevada	Yes	Yes	n/a
New Hampshire	Yes	Yes	n/a
New Jersey	Yes	No	Department of Children and Families
New Mexico	Yes	No	Behavioral Health Services Division, Department of Health
New York	Yes	Yes ³	n/a
North Carolina	Yes	No	Division of Mental Health, Developmental Disabilities and Substance Abuse, Department of Health and Human Services
North Dakota	Yes	Yes	n/a
Ohio	Yes	Yes	n/a
Oklahoma	Yes	Yes	n/a
Oregon	Yes	No	Addictions and Mental Health Services, Department of Human Services
Pennsylvania	Yes	No	Office of Mental Health and Substance Abuse Services, Department of Public Welfare
Rhode Island	No	No	Developmental Disabilities and Hospitals, Department of Behavioral Healthcare,
South Carolina	Yes	Yes	N/a Division of Community Debayiaral Uselth Department of Cosial Corvises
South Dakota	Yes	No	Division of Community Behavioral Health, Department of Social Services
Tennessee	Yes	Yes	N/a Department of State Health Services
Texas Utah	Yes Yes	No Yes	Department of State Health Services n/a
Vermont	Yes	No	Department of Mental Health
Virginia	Yes	Yes	
Washington	No	No	n/a Division of Behavioral Health and Recovery, Department of Social & Health Services
Washington West Virginia	Yes	Yes	n/a
Wisconsin	Yes	No	Division of Mental Health and Substance Abuse Services, Department of Health Services
Wyoming	Yes	No	Behavioral Health Division, Department of Health

Note: LTSS refers to long-term services and supports.

1 Most behavioral health services for Medicaid enrollees (except for certain members) were consolidated under MedQuest, effective September 2013. The Adult Mental Health Division, Department of Health retains responsibilities for crisis and court-ordered treatment services.

2 KanCare includes behavioral health benefits, but policy, licensure, and program development remains with the Department of Aging and Disability Services.

3 Office of Mental Health is responsible for operation of state public mental health system, rate setting, and Medicaid Behavioral Health Organization initiative for Medicaid managed care enrollees.

Source: State website search, 2013.

State	Nursing Facility		ICF/ID		Mental Health Facility <21	Personal Care	1915(c) HCBS Waiver ¹	1915(i) HCBS ²	1915(j) Personal Assistance ³	1915(k) Community First Choice ²	Private Duty Nursing	Rehab- ilitation	Targete Case Manage ment ³
Total	51	51	48	46	51	31	48	15	1	3	23	51	40
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Arkansas	\checkmark	\checkmark	\checkmark	v	✓ ✓	\checkmark	\checkmark				✓ ✓	✓ ✓	\checkmark
California	V V	V	V	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	v	✓ ✓	V V
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Florida	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	\checkmark	\checkmark			\checkmark	\checkmark
Georgia	\checkmark	\checkmark	\checkmark		\checkmark		\checkmark					\checkmark	\checkmark
Hawaii	\checkmark	\checkmark	\checkmark		\checkmark		\checkmark					\checkmark	\checkmark
Idaho	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark				\checkmark	\checkmark
Illinois	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark					\checkmark	\checkmark
Indiana	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	\checkmark			\checkmark	\checkmark	\checkmark
lowa	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark	\checkmark				\checkmark	
Kansas	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark		\checkmark					\checkmark	\checkmark
Kentucky	\checkmark	\checkmark	\checkmark	1	\checkmark		\checkmark					\checkmark	\checkmark
Louisiana	\checkmark	\checkmark	1	1	\checkmark	\checkmark	\checkmark	\checkmark				1	
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APPENDIX TABLE 2-A-4. Medicaid Long-Term Services and Support (LTSS) Benefits by State

Notes: FY refers to fiscal year. HCBS refers to home and community-based services. ICF/ID refers to intermediate care facilities for individuals with intellectual or developmental dissabilities. Although these Medicaid benefits are listed in statute, the breadth of coverage (i.e., amount, duration, and scope) and included services within specific benefits (e.g., HCBS) varies by state. The table lists Medicaid LTSS benefits that are described in federal statute or regulations and reflect available benefits as of October 2012, except where noted. The presence of a service within a states' benefit package does not always mean that enrollees are able to utilize those services.

1 Four states (AZ, HI, RI, VT) provide HCBS via Section 1115 waiver. This number is different from the three states mentioned in the text of the chapter because of the different source years used for the data.

2 Includes only states that have submitted state plan amendments (including those who have not yet received approval) as of November 2013 for 1915(i) and as of April 2014 for 1915(k).

3 Information on Section 1915(j) and targeted case management was derived from expenditures reported by states in FY 2013.

Sources: KCMU 2014b, NASUAD 2014, NASUAD 2013, MACPAC analysis of CMS-64 Financial Management Report (FMR) net expenditure data as of February 2014.