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Advocate's Guide

Medicaid Long Term Services & Supports 101: Emerging Opportunities and Challenges

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Table of Contents

Acknowledgments

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Introduction

Medicaid, the joint federal-state program that provides healthcare coverage for certain groups of low-income individuals, is the single largest purchaser of long-term services and supports (LTSS) in the United States. LTSS services are those that help older adults and people with disabilities manage chronic conditions, as well as accomplish everyday tasks such as bathing, getting dressed, fixing meals, or managing a home. LTSS services include residential care in facilities like nursing homes. But they also include home and community-based service options (HCBS) such as home health care, personal care assistance, adult day care and homemaker services that help meet peoples' needs without institutional placement. As our population ages, the number of individuals needing help of this kind is projected to double.

Medicaid consistently spends more on institutional care than community-based care for beneficiaries with LTSS needs. Over the years, Congress has gradually expanded Medicaid's community-based service options, but the balance of expenditures still falls on the side of nursing homes and other facilities. The current legal and political landscape presents both great opportunities to expand low-income individuals' ability to receive needed LTSS services at home, and tremendous challenges for maintaining current access to such programs.

On one hand, in passing the Patient Protection and Affordable Care Act (ACA) in 2010, Congress took arguably its most aggressive action toward "rebalancing" Medicaid's LTSS spending in nearly three decades. At the same time, recession-related state budget shortfalls have put hundreds of Medicaid home and community-based LTSS benefit programs at risk. While states participating in Medicaid are required to provide nursing home services, coverage of most in-home services and supports is optional – making them an easy target for policymakers looking for a quick fix to state budget woes.

This guide offers advocates a primer on the law that impacts Medicaid-funded home and community-based services. It also highlights key resources and tools to use when advocating to expand and preserve Medicaid coverage of critical LTSS services in individual states.

Part I (Survey of Community-Based LTSS Program Options) explains different programs states can use to provide home and community-based LTSS through Medicaid, including new ACA programs and managed care delivery systems.

Part II (Legal Protections 101) gives an overview of the federal standards and requirements that protect access to community-based Medicaid services,

including disability rights laws, the Medicaid Act, and due process.

Part III (Advocacy Issues) identifies trends in Medicaid LTSS and offers strategies to help advocates ensure that program changes work to the benefit of Medicaid consumers.

Each of these parts is paired with an annotated Resources table that features useful related resource materials, including issue briefs, legal primers, federal policy guidance, policy whitepapers, and advocacy tools.

Finally, a table of Recent Notable Cases offers summaries of some recent, noteworthy court challenges to community-based LTSS program cuts, as well as other cases that bear on advocates' ability to defend against such cuts in the future.

I. Survey of Community-Based LTSS Program Options

Medicaid gives states significant flexibility to determine which services to cover, particularly with respect to home and community- based services (HCBS). In fact, the only non-institutional long-term benefit states are *required* to cover is home health for individuals who would qualify for nursing home care. All other non-institutional LTSS, including personal care assistance, homemaker services, and adult day care, are so-called "optional" services, meaning that state Medicaid programs can *decide* whether or not to offer them.[1] Not surprisingly, the configuration of community-based services and supports available to Medicaid participants varies dramatically from state to state.

Most states do cover some combination of community-based services or supports. They can use an array of program, service and delivery vehicles to do so, each with its own rules and requirements. This section explains and highlights significant and/or recently-enacted programs states can use to offer LTSS at home or in the community: A) traditional state plan services, B) waivers (including HCBS and demonstration waivers), C) other options for community-based LTSS (including the Self-Directed Personal Assistance Program, the Program for All-Inclusive Care For the Elderly (PACE), the HCBS state plan option, Community-First Choice (CFC), and the Balancing Incentives Payment Program (BIPP)), and D) managed care.

A. Traditional State Plan Services

Traditionally, for a service to be covered under a state's Medicaid program, that service must be included in its Medicaid State Plan. To participate in Medicaid, states develop state plans that describe the scope and nature of their Medicaid program, including what services will be covered and for whom. Each state's plan must be approved by the federal Centers for Medicare and Medicaid Services (CMS). (*See* Part II.B.)

Under the rules of the Medicaid program, a state's plan must cover at least certain "mandatory" services, including home health services for individuals who satisfy the clinical criteria for nursing home placement. State plans may also offer other optional LTSS services, such as personal care and private duty nursing, as part of the general Medicaid

1 Optional community-based LTSS that states can choose to cover include: home health care for individuals who do not meet nursing home clinical criteria, private duty nursing, hospice care, case management, home and community care (homemaker/home health aide services, chore services, personal care services, nursing care services, respite care, adult day care for functionally disabled elderly individuals), community-supported living arrangement services (personal assistance, training and habilitation services, 24-hour emergency assistance, assistive technology, adaptive equipment for individuals with developmental disabilities), personal care services, and PACE (*see* Part II.C.ii.).

benefit package. As of 2008, all 50 states, plus the District of Columbia, offered home health services through their state plans and 32 states did the same for personal care services.

Key Sources of Law

State Plan Requirements:
42 U.S.C. § 1396a(a)

Mandatory Services:
42 U.S.C. § 1396a(a)(10)(A), (D)

Medicaid Service Categories:
42 U.S.C. § 1396(d)(a)

All services included in a state's regular state plan benefit package – whether optional or mandatory – are entitlements: they must be available to any person in the state who meets the relevant financial and clinical standards. They also must comply with the requirements of federal Medicaid law discussed in Part II.B. LTSS services offered as part of a state's regular state plan benefit package are subject to the same rules, including the requirement that covered services be available statewide, and that comparable services be provided to beneficiaries with comparable medical needs. (*See* Part II.B.) Within those limits, however, states have the flexibility to decide the scope of services available and any relevant eligibility criteria.

B. Medicaid Waivers

As described above, services provided through state plans, including home and community-based LTSS, have to be administered in a way that meets all the requirements of the Medicaid Act. However, the Medicaid statute also authorizes a number of "waiver" programs through which states can get approval from the Centers for Medicare and Medicaid Services (CMS) to waive certain requirements when providing certain services or serving certain populations. There are two main waiver programs states can use to provide community-based long-term services and supports: Home and Community-Based Services (HCBS) waivers and demonstration waivers. LTSS services provided through these waivers are subject to the particular rules associated with each program, and any general Medicaid Act requirements that haven't been explicitly waived by CMS.

i. HCBS Waivers

The Home and Community-Based Services (HCBS) waiver program allows states to offer community-based LTSS service packages to individuals whose care needs would otherwise qualify them for Medicaid-funded institutional care in nursing homes, hospitals, or intermediate care facilities for those with mental retardation (ICF/MR). There is no limit on the number of HCBS waivers a state can operate; currently, there are more than 300 active HCBS waiver programs operating in 47 states and the District of Columbia.

HCBS waivers, sometimes called Section 1915(c) waivers after the Social Security Act Section that created them, can offer a broad combination of medical and non-medical community-based LTSS.[2] Benefits can include case management, home health aide services, personal care, adult day health care, and respite care, as well as other services states

2 A similar HCBS waiver, authorized under Section 1915(d), allows states to provide community-based LTSS to adults age 65 and older.

were not previously permitted to offer as state plan entitlements. In addition, states can propose "other" types of services, such as home modification assistance, aimed at diverting or transitioning individuals from institutional settings into the community.

HCBS waivers permit states to restrict and/or expand coverage for these services in ways they can't for state plan entitlements:

- **Cost Limits**. Under the HCBS waiver program, the costs of care cannot exceed those for comparable services in an institutional setting.[3] In contrast, when services are strict entitlements, eligible individuals have the right to receive as much care as is necessary to meet their needs, regardless of cost.
- **Geographic Limitations**. States can request to waive Medicaid's statewideness requirement (*see* Part II.B) and limit coverage for particular services to certain geographic regions.
- **Population Targeting and Enrollment Caps**. States can ask to waive Medicaid's comparability requirement (*see* Part II.B) and limit coverage to a particular population, such as the elderly, those with physical disabilities, or those with HIV/AIDS. States can also waive comparability to limit the number of people who can access services through a particular waiver. If more residents qualify for an HCBS waiver than there are "slots" available, states can maintain waiting lists – something they are not allowed to do for state plan services.
- **Relaxed Income and Resource Rules**. Financial requirements for Medicaid eligibility are generally more restrictive for individuals who live in the community than for those in institutions. However, because individuals must meet the clinical standards for institutional care to get 1915(c) waiver services, states can waive the community resource and income rules and use institutional financial standards for all waiver participants, even if they live at home. Individuals who enroll in an HCBS waiver under this special income category are entitled to full Medicaid benefits.

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1396n(c)(1)

Special Income Category:
42 C.F.R. § 435.217

HCBS Waiver Requirements:
42 C.F.R. § 441.300-.310

HCBS Waiver Services:
42 C.F.R. § 440.180

In order to offer community-based LTSS services through an HCBS waiver, states submit a waiver application to CMS. That application explains the contours of the proposed HCBS program, including the services to be provided, the target population, service eligibility criteria, and which Medicaid Act requirements the state wishes to waive. Waivers must be renewed and reapproved by CMS every three to five years.

3 States can cap costs individually (so that the costs of a particular individual's care in the community cannot exceed the cost of comparable institutional care for that person) or on an aggregate basis (so that the total cost of community-based care for all waiver participants does not exceed the total amount it would cost to serve that population in institutional settings).

ii. Medicaid Demonstration Waivers

States may also choose to offer LTSS through a demonstration waiver. Section 1115a of the Social Security Act gives states the option to design experimental pilot projects, known as Section 1115 waiver or demonstration waiver programs, aimed at finding better ways to administer and promote the goals of the Medicaid program. In designing these demonstrations, states can ask CMS to waive any of the requirements in Section 1396a of the Medicaid Act, among others, to the extent necessary to carry out the pilot. Currently, there are over 80 active Section 1115 waivers.

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1315

Application, Review, and Public Input Rules:
42 C.F.R. § 431.400-.428

Section 1115 waivers offer states tremendous flexibility. They can be used to do things as diverse as changing Medicaid eligibility rules, moving to managed care financing and delivery models (*see* Part I.D), or offering coverage for services not traditionally available through Medicaid, including certain LTSS that couldn't historically be offered as state plan services.

This flexibility, however, does have limits: courts have interpreted the Medicaid statute to authorize CMS approval of Section 1115 waivers only where the proposed project actually seeks to test or demonstrate something (*e.g.*, the potential for cost savings or better health outcomes), is likely to assist in promoting the objectives of the Medicaid Act, and is limited in scope and duration to that necessary to achieve its demonstration purpose. Demonstrations must be budget neutral to the federal government, meaning the project can't require the federal government to contribute more than it would have without the waiver. Demonstration waivers also cannot be used to waive Medicaid rules other than those specifically enumerated in Section 1115a, nor requirements imposed by the Constitution or other federal laws, such as the Americans with Disabilities Act. (*See* Parts II.C, II.A.)

To obtain a Section 1115 waiver, states submit to CMS a waiver application which details, among other things, the purpose of the demonstration, the services to be provided, eligibility rules, and the Medicaid Act requirements to be waived. In general, demonstration waivers are approved for a five-year period and can be renewed, typically for an additional three years.

Because demonstration waivers can make sweeping changes to the traditional Medicaid programs rules, the ACA added a requirement for greater transparency and established an opportunity for public comment during the application review process. States are required to post proposed demonstration waiver applications and any accompanying documents online at least 30 days prior to their submission to CMS. States must also hold at least two public hearings at least 20 days prior to submission of the demonstration proposal. At the federal level, CMS is required to provide at least a 30-day comment period. The application and any public comments are also posted online, along with any special terms and conditions imposed by CMS if and when the application is approved.

1115A Dual Eligible Demonstrations

Section 1115A of the Social Security Act, enacted as part of the Affordable Care Act, grants CMS wide discretion to approve demonstration projects that test changes to Medicare and/or Medicaid to see whether they save money while maintaining or improving quality. As of July 1, 2012, 26 states have submitted proposals for financial alignment demonstration projects that would integrate the delivery of Medicaid and Medicare benefits for individuals dually eligible for both programs (dual eligibles). The majority of these dual eligible demonstration proposals, if approved, would enroll dual eligibles into capitated managed care plans responsible for providing all Medicare and Medicaid services, including LTSS.

Section 1115A authority is distinct from that available to states under the Section 1115a Medicaid demonstration waiver; states approved to integrate Medicaid and Medicare services through a Section 1115A demonstration still need separate authorization – through a Medicaid waiver or state plan amendment – in order to make changes to their Medicaid LTSS programs. For example, if a state seeks to require dual eligibles to enroll in Medicaid managed care as part of its dual eligible demonstration, the state will need to both get its dual eligible demonstration approved *and* apply for a Section 1915(b) or Section 1115a waiver that will permit them to do that. (*See* Part II.D.)

Additional information on dual eligible demonstrations is available at *www.dualsdemoadvocacy.org*. Additional information on Medicare coverage and advocacy can be found at *www.medicareadvocacy.org*.

C. Other Options for Community-Based LTSS

Since enacting Section 1915(c) in 1981, Congress has continued to authorize new, albeit less heavily utilized, Medicaid programs through which states can offer community-based services and rebalance LTSS expenditures away from institutional care. Other community-based LTSS program options of note include: i) the Self-Directed Personal Assistance Program, ii) the Program of All-Inclusive Care for the Elderly (PACE), iii) the HCBS state plan option, iv) Community First Choice (CFC), and v) the Balancing Incentive Payment Program (BIPP). The three latter programs were all either created or substantially amended in 2010 by the Affordable Care Act (ACA), which represents arguably the most aggressive action in the post-HCBS waiver rebalancing effort to date.

i. Self-Directed Personal Assistance Program

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1396n(j)

Regulations:
42 C.F.R. §§ 441.450-.484

Self-directed personal assistance services (PAS), also known as 1915(j) services, involve both personal care and related services. States can provide PAS as an HCBS state plan option benefit (*see* Part I.C.iii) or through a 1915(c) waiver (*see* Part I.B.i). States have the option to waive Medicaid's comparability requirement with respect to PAS (*see* Part II.B), and can also provide it to people who would otherwise only be financially eligible for Medicaid based on less restrictive institutional income criteria.

Beneficiaries who choose PAS are able to hire and train their own homecare providers, rather than going through a licensed homecare agency. Relatives and friends can serve as providers. This can include parents or spouses if the state chooses. States can also choose to give beneficiaries cash disbursements rather than paying providers. A person-centered planning process and an individualized plan of care is required.

ii. Program of All-Inclusive Care for the Elderly (PACE)

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1396u-4

The Program for All-Inclusive Care for the Elderly (PACE) is a state plan optional benefit that includes LTSS and other health services. It is a relatively small program, available only to people who live within a PACE organization's service area. Eligibility is limited to those 55 years or older and clinically eligible care in a nursing home. PACE organizations are responsible for providing all Medicare and Medicaid services to their enrollees. Enrollment is voluntary; eligible participants can choose to enter or leave any time. PACE has its own unique integrated appeals process.

PACE organizations, almost all of which are non-profit or public, have a reputation as successful providers of integrated LTSS and health services. However, states have found it difficult to implement PACE on a large scale.

iii. HCBS State Plan Option

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1396n(i)

The HCBS state plan option, which was substantially amended and enhanced as part of the Affordable Care Act, allows states to offer as state plan services the same types of community-based LTSS available through the HCBS waiver. The HCBS state plan option is similar to the HCBS waiver in that it lets states waive Medicaid's comparability requirement (*see* Part II.B) to limit program benefits to particular populations. However, it does not allow states to maintain waiting lists or limit services to particular areas of the state.

In addition, unlike under HCBS waivers, an individual does not have to qualify for institutional care in order to receive services through the state plan option; rather, states are required to make their state plan option clinical eligibility criteria less stringent than those for nursing home services. If state plan option enrollment exceeds projected estimates, states can (after giving CMS and the public 60 days advance notice) modify non-financial eligibility standards to try to reduce the eligible population. Grandfathering provisions protect those who were receiving LTSS prior to the adoption of the state plan option from losing services as a result of these changes.

People with incomes up to 150 percent of the federal poverty level are eligible, and the state can also choose to include those who otherwise would be eligible under an HCBS or demonstration waiver, so long as the person's income does not exceed 300 percent of the federal Supplemental Security Income (SSI) benefit.

iv. Community First Choice Option (CFC)

The Community First Choice option (CFC), also enacted as part of the ACA in 2010, gives state Medicaid programs incentives to offer more extensive HCBS by increasing the federal Medicaid match by six percent for HCBS that meet CFC standards. Because CFC is provided through a state plan amendment rather than a waiver, CFC benefits must be made available throughout a state, not limited by enrollment caps or geographical restrictions, for example.

Key Sources of Law

Authorizing Statute:
42 U.S.C. § 1396n(k)

Regulations:
42 C.F.R. §§ 441.500 - .590

Beneficiaries must need nursing home care or the equivalent. Financial eligibility for CFC requires income not exceeding 150 percent of the federal poverty level or, alternatively, not exceeding the state's special income limit for persons needing nursing home care (generally 300 percent of the federal SSI benefit).

CFC services can be made available through an agency-provider model, or through a

consumer-directed model.[4] Individual beneficiaries have discretion to set standards for service providers, with the additional requirement in an agency-provider model that states "define in writing adequate qualifications for providers." Family members can be hired from a service budget, as long as the family member has been trained to the beneficiary's satisfaction.

v. Balancing Incentive Payments Program (BIPP)

The State Balancing Incentive Payments Program (BIPP), another ACA enactment, is a temporary program that provides extra money to incentivize change in states whose current Medicaid spending for community-based LTSS is less than that for LTSS in facilities. To date, eight states have been approved to participate in BIPP.
In making a BIPP application to CMS, a state commits itself to spend either 25 or 50 percent (or more) of its LTSS Medicaid budget on community-based services. The 25 percent target applies to those states whose HCBS expenditures are currently under 25 percent of their total LTSS spending; the 50 percent target applies to those states currently between 25 and 50 percent. State strategies for meeting these targets must include a no-wrong-door entry point system, conflict-free case management, and a standardized assessment agreement.

Key Sources of Law

Affordable Care Act § 10202

If a state's target is 25 percent, it will receive a five percent increase in its federal Medicaid match for non-institutional LTSS expenditures. For states with a target of 50 percent, however, the increase in the match declines to two percent.

vi. Money Follows the Person

The Money Follows the Person (MFP) program was authorized by 2005's Deficit Reduction Act (DRA). Through MFP, Congress authorized payment of $1.75 billion over five years for state efforts to transition Medicaid-enrolled nursing home residents to the community. Medicaid money "follows" the Medicaid beneficiary from a nursing home or other institution to a community-based setting. For the first 12 months after the move to the community, the state's Medicaid program receives an increased federal reimbursement rate for LTSS provided to the beneficiary.

MFP assistance initially was available only to persons who had resided in an institution for at least six months; this prerequisite was reduced to 90 days in 2012. MFP is currently scheduled to last until 2016.

Forty-three states and the District of

4 An agency model is one where the caregiver is employed by a service provider agency that receives Medicaid reimbursement for services provided and pays the caregiver a wage. A consumer-directed model is one where the caregiver is employed and directed solely by the beneficiary. In the consumer-directed model, Medicaid reimbursement can be routed through a fiscal agent, or take the form of vouchers, or cash payments directly to the beneficiary.

Columbia are participating in MFP. The program originally got off to a slow start, however, as fewer people have transitioned out of institutions than anticipated. Challenges to implementation of MFP have included lack of safe, affordable housing, and, in some states, lack of support for program administration.

Key Sources of Law

Authorizing Legislation:

DRA § 6071, as modified by ACA § 2403 (notes to 42 U.S.C. § 1396a)

D. Managed LTSS

Traditional Medicaid operates under a fee-for-service (FFS) model, meaning that states directly reimburse providers, including long-term care providers, for each approved service beneficiaries receive. States can also elect to utilize managed care delivery systems, in which Medicaid services are provided by a private organization contracted with the state.

Medicaid managed care programs vary widely. States can contract with health plans, also called managed care organizations (MCOs), to provide all or most of an enrolled beneficiary's Medicaid services in exchange for a capped monthly payment. States can contract with limited benefit plans to provide only particular service packages like LTSS or mental health services. Or they can pay primary care case managers (PCCMs) a fee to both act as a beneficiary's primary care provider and coordinate and arrange any outside services. Some states make enrollment in managed care optional; in others, enrollment is mandatory. States can elect to enroll all Medicaid beneficiaries or restrict enrollment to specific populations.

Historically, long-term services and supports were carved out of Medicaid managed care – *i.e.*, explicitly excluded from the list of covered services plans were required to provide. The state continued to pay providers directly for carved-out services on a fee-for-service basis, even for managed care enrollees. However, states are increasingly integrating LTSS services into managed care. The number of states with managed LTSS programs has grown from eight in 2004 to 16 in 2012; that number is expected to increase to 26 by 2014.

States can use four different kinds of statutory provisions to enroll beneficiaries into managed care – the Section 1932(a) state plan authority or the Section 1915(a), 1915(b), or 1115a waiver authorities. (*See* Part I.B.ii.) Each of these authorities can be used to offer any state plan service, including state plan long-term services and supports, through managed care. To offer managed care coverage of community-based LTSS services that aren't included in its state plan, a state can either use a Section 1115 waiver to establish its program, or combine any of the other managed care authorities with a Section 1915(c) HCBS waiver.

To mandatorily enroll individuals dually-eligible for both Medicaid and Medicare –among the heaviest users of LTSS services– into Medicaid managed care, states can use

either a Section 1915(b) waiver or a Section 1115 waiver.[5]

All four managed care authorities allow states to waive the Medicaid Act rules on statewideness (to limit managed care programs geographically), comparability (to offer certain services exclusively to beneficiaries enrolled in managed care), and freedom of choice (to restrict enrollees' choice of providers to those in the plans' network). (*See* Part II.B.) In addition, whatever authority a state uses, it must comply with general Medicaid regulations that set managed care program standards in areas including health plan quality, appeal and grievance rights, provider access.

Key Sources of Law

State Plan Authority:
42 U.S.C. § 1396u-2

1915(a) Authority:
42 U.S.C. § 1396n(a)

1915(b) Authority:
42 U.S.C. § 1396n(b)

1115a Authority:
42 U.S.C. § 1315

General Managed Care Rules:
42 U.S.C. § 1396b(m) (MCOs)
42 U.S.C. § 1396d(t) (PCCMs)
42 C.F.R. § 438

5 Mandatory enrollment of dual eligibles into managed care is a component of many of the Section 1115A dual eligible demonstration proposals currently under consideration by CMS. (*See* 1115A Dual Eligible Demonstrations inset, Part I.B.ii.) The Section 1932(a) state plan authority does not permit mandatory enrollment of certain populations, including dual eligibles. Section 1915(a) permits states to create voluntary managed care programs, but does not allow any mandatory enrollment whatsoever.

Resources: Survey of Community-Based LTSS Program Options			
	Resource and Citation	Description	Electronic Link
		A. Traditional State Plan Services	
1	Kaiser Commission on Medicaid and the Uninsured, *Medicaid Home and Community-Based Services Programs: Data Update* (Dec. 2011)	Issue brief analyzing national trends over ten years (ending in 2008) in participation and expenditures in Medicaid home- and community-based services, including the home health state plan benefit and the personal care services state plan benefit.	*www.kff.org/medicaid/upload/7720-05.pdf*
		B. Medicaid Waivers	
2	Medicaid.gov, *Waivers*	Online, state-by-state list of waiver types and links to copies of waiver agreements with states.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html*
3	The SCAN Foundation, *Long Term Care Fundamentals: What is a Waiver?*, Technical Brief Series No. 8 (Aug. 1, 2011)	Explains the various waivers available to states under Medicaid and describes those Medicaid waivers operational in California as of the date of publication.	*www.thescanfoundation.org/what-medicaid-waiver*
4	National Health Law Program, *Federal Medicaid Waivers*, THE ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM 2.7 (June 2011)	Section of comprehensive Medicaid treatise exploring each waiver authority in depth. Draws from and compiles relevant Medicaid statutes and regulations, as well as federal guidance documents, and federal and state court case law.	Purchase or subscription only: *healthlaw.org/index.php?option=com_c1ontent&view=article&id=110&Itemid=183*
		i. HCBS Waivers	
5	Medicaid.gov, *Home & Community-Based Services 1915(c)*	Online federal government resource explaining rules and guidelines of 1915(c) Waiver program.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-c.html*
6	Kaiser Commission on Medicaid and the Uninsured, *Medicaid Home and Community-Based Services Programs: Data Update*	Issue brief analyzing national trends over ten years (ending in 2008) in participation and expenditures in Medicaid home- and community-based services, including 1915(c) waivers.	*www.kff.org/medicaid/upload/7720-05.pdf*

Resources: Survey of Community-Based LTSS Program Options			
	Resource and Citation	**Description**	**Electronic Link**
7	Centers for Medicare and Medicaid Services, *Application for a § 1915(c) Home and Community-Based Waiver (Version 3.5): Instructions, Technical Guide and Review Criteria* (Jan. 2008)	Federal guidance on requirements of an HCBS Waiver, as well as instructions for completing the application, review and renewal.	*www2.ancor.org/issues/medicaid/07-28-08_Version_3.5_Instructions.pdf*
8	Center for Personal Assistance Services, *Home and Community PAS Based Programs*	Online repository for state-by-state data on participants, services, and expenditures in Medicaid community-based LTSS programs, particularly 1915(c) Waivers. Collected as part of a 5-year research project to study HCBS trends over time.	*www.pascenter.org/home_and_community/index.php#reports*
	ii. Medicaid Demonstration Waivers		
9	Medicaid.gov, *Section 1115 Demonstrations*	Online resource explaining basics of 1115 Demonstration program, application process and public input rules. Offers link to all demonstration proposals submitted to CMS, including all active, pending, denied, and/or expired 1115 Waivers.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/1115/Section-1115-Demonstrations.html*
10	Kaiser Commission on Medicaid and the Uninsured, *An Overview of Recent Section 1115 Medicaid Demonstration Waiver Activity* (May 2012)	Policy brief describing recent developments and trends in states' use of Section 1115 demonstration waivers. Also provides background on the Section 1115 authority, key elements of the waiver application, and the demonstration approval process.	*www.kff.org/medicaid/upload/8318.pdf*
11	National Senior Citizens Law Center, *Dual Eligible Integrated Care Demonstrations*	Information for advocates about dual eligible integrated care demonstration projects, including repository of comments from advocates on states' 1115 duals demonstration proposals.	*dualsdemoadvocacy.org*

Resources: Survey of Community-Based LTSS Program Options

	Resource and Citation	Description	Electronic Link
		C. Other Options for Community-Based LTSS	
		i. Self-Directed Personal Assistance Services Program	
12	Medicaid.gov, *Self-Directed Personal Assistant Services 1915(j)*	Online resource explaining basic 1915(j) guidelines and rules. Includes links to additional federal guidance, as well as information about self-directed services generally.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Self-Directed-Personal-Assistant-Services-1915-j.html*
13	Centers for Medicare and Medicaid Services, State Medicaid Director Letter # 09-007 (Nov. 19, 2009)	Federal guidance on the implementation of 1915(j).	*downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD111909.pdf*
		ii. Program of All-Inclusive Care for the Elderly (PACE)	
14	Medicaid.gov, *PACE*	Online resource explaining basic PACE guidelines and rules. Includes links to additional resources like the PACE Manual – a compilation of detailed program rules for providers – and information for state about their responsibilities in administering the program.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Integrating-Care/Program-of-All-Inclusive-Care-for-the-Elderly-PACE/Program-of-All-Inclusive-Care-for-the-Elderly-PACE.html*
		iii. HCBS State Plan Option	
15	National Senior Citizens Law Center, *The Medicaid Long-Term Services Provisions in the Health Reform Law* (April 2010)	Issue brief explaining and providing commentary on BIPP, CFC, and HCBS state plan option programs as authorized under the ACA.	*www.nsclc.org/wp-content/uploads/2011/07/Medicaid-LTSS-Provisions-on-Health-Reform-Law.pdf*
16	Medicaid.gov, *Home & Community-Based Services 1915(i)*	Online resource explaining 1915(i) guidelines, rules, and state application and approval processes.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Home-and-Community-Based-Services/Home-and-Community-Based-Services-1915-i.html*

Resources: Survey of Community-Based LTSS Program Options

	Resource and Citation	Description	Electronic Link
17	Centers for Medicaid and Medicare Services, *Re: Improving Access to Home and Community-Based Services*, State Medicaid Director Letter # 10-015 (Aug. 6, 2010)	Federal guidance explaining the changes to the HCBS state plan option enacted by the ACA, the requirements to qualify for the program, and procedures for states to submit state plan amendment applications to participate.	*downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/SMD10015.pdf*
18	National Senior Citizens Law Center, *Comments on Proposed Regulations for State Plan HCBS* (July 2, 2012)	Comment letter analyzing and recommending additional changes to proposed regulations implementing the ACA's changes to the HCBS state plan option.	*www.nsclc.org/wp-content/uploads/2012/07/comments-on-HCBS-state-plan-regs-NSCLC-7-2-12.pdf*
	iv. Community First Choice Option (CFC)		
19	Families USA, *Long Term Services Health Reform Provisions: Community First Choice Option*	Online resource that explains rules and guidelines for CFC program, with links to other relevant materials.	*www.familiesusa.org/issues/long-term-services/health-reform/community-first-choice-option.html*
20	Medicaid.gov, *Balancing Incentive Program*	Online resource explaining BIPP rules and guidelines, as well as postings of all approved state applications to participate in the BIPP program.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Balancing/Balancing-Incentive-Program.html*
21	Justin Foley, Service Employees International Union Healthcare Research, *BIPP Annual FMAP Increase Estimates*	Table estimating the amount of additional federal matching funds each state and the District of Columbia could generate for their Medicaid programs each year by participating in BIPP.	*www.ncoa.org/assets/files/pdf/public-policy--action/SEIU-Analysis-Anticipated-BIPP-Reimbursement-JF-073012.pdf*
22	Lina Walker, AARP Public Policy Institute, *Health Care Reform Improves Access to Medicaid Home and Community-Based Services* (June 2010)	Fact sheet offering a summary of the community-based LTSS changes made by the ACA, including the enactments of BIPP and CFC, and the amendments to the HCBS state plan option.	*assets.aarp.org/rgcenter/ppi/ltc/fs192-hcbs.pdf*

Resources: Survey of Community-Based LTSS Program Options			
	Resource and Citation	**Description**	**Electronic Link**
	D. Managed LTSS		
23	Medicaid.gov, *Managed Care*	Online resource that explains various options for authorizing Medicaid managed care programs. Includes links to relevant state waiver applications.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Managed-Care/Managed-Care.html*
24	Centers for Medicare and Medicaid Services, *The Growth of Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 Update* (July 2012)	White paper that inventories all current MLTSS programs and projects future programs. Reports on multiple program features, enrollment, and characteristics of managed care contracts. Includes state-by-state results and synthesized national results.	*www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf*
25	Centers for Medicare and Medicaid Services, *Managed Long Term Services & Supports: Resources for State Policy and Program Development*	Online resources for state policy makers engaged in managed LTSS program design, including explanations of universal managed care features, program design options, and available program vehicles, as well as case studies, worksheets and sample managed care contracts.	*www.medicaid.gov/mltss*
26	Kaiser Commission on Medicaid and the Uninsured, *Examining Medicaid Managed Long-Term Services and Support Programs: Key Issues to Consider* (October 2011)	Issue brief offering background on managed LTSS programs. Identifies key issues states should consider when covering new populations and LTSS benefits through capitated payments to traditional risk-based managed care organizations.	*www.kff.org/medicaid/upload/8243.pdf*

II. Legal Protections 101

Medicaid-funded community-based long-term service benefits are subject to a range of statutory and constitutional restrictions that offer advocates potential tools to preserve and expand individuals' access to Medicaid LTSS at home and in the community.

The availability of community-based alternatives to institutionalization implicates federal disability rights laws, which recognize that segregation of individuals with disabilities from the community is a form of discrimination. In addition, as with other Medicaid services, states must administer LTSS in a way that is consistent with the specific rules of the Medicaid program or programs through which the services are offered (*see* Part I), as well as all general Medicaid Act requirements not waived by CMS. In addition, because Medicaid beneficiaries have a property right in LTSS services, states must comply with the strictures of due process when making coverage decisions. Each state Medicaid program is also, of course, subject to its own state-specific laws, including any corollary state administrative procedure, due process or anti-discrimination statutes or constitutional provisions.

This section explores the three primary categories of federal protections that apply to Medicaid community-based services and supports: disability rights laws, substantive Medicaid Act protections, and constitutional and statutory due process requirements. This survey is by no means an exhaustive list of the legal requirements that apply to any particular state Medicaid program. Instead, it is intended to provide an overview of the legal lattice that protects community-based Medicaid LTSS and to spotlight some of the federal laws that may be most useful to state advocates seeking to influence the contours of those programs.

A. Disability Rights Laws

Title II of the Americans with Disabilities Act (ADA) prohibits state and local governments from discriminating against an individual with a disability by excluding that person from or denying benefits or services on the basis of that disability. Section 504 of the Rehabilitation Act of 1973, on which the ADA is modeled, sets forth similar protections against discrimination by recipients of federal funds against individuals on the basis of disability. Both laws apply to state administration of Medicaid programs, including Medicaid LTSS programs, which are partially funded by federal dollars.

Regulations implementing Title II and Section 504 specify that public entities (or their contractors) are prohibited from administering programs using criteria or methods of administration that have the effect of discriminating on the basis of disability, whether intentional or not. Likewise, states cannot use eligibility criteria that screen out or even tend to screen out individuals or classes of individuals with disabilities from "fully and equally enjoying any service, program, or activity," unless those criteria are a necessary part of the service, program, or activity offered.

Key Sources of Law

ADA, Title II: 42 U.S.C. § 12132

Rehab Act, Sec. 504: 29 U.S.C. § 794

Methods of Administration:
28 C.F.R. § 35.130(b)(3) (ADA)
28 C.F.R. § 41.51(b)(3)(I) (Rehab Act)
45 C.F.R. § 84.4(b)(4) (Rehab Act)

Improper Eligibility Requirements:
28 C.F.R. § 35.130(b)(8) (ADA)
45 C.F.R. § 84.4(b)(1)(iv) (Rehab Act)

Reasonable Accommodations/ Modifications:
28 C.F.R. § 35.130(b)(7) (ADA)
28 C.F.R. § 41.53 (Rehab Act)

Integration Mandate:
28 C.F.R. § 35.130(d) (ADA)
28 C.F.R. § 41.51(d) (Rehab Act)
Olmstead v. L.C. ex rel. Zimring, 527 U.S. 581 (1999)

Under the ADA and Rehabilitation Acts, a state is not required to fundamentally alter a program or a service to accommodate the needs of a person with a disability, but it can be required to make a "reasonable accommodation." Thus, states are required to make "reasonable modifications" to policies or practices when necessary to avoid disability discrimination, unless they can show that doing so would be a fundamental alteration.

Both the ADA and the Rehabilitation Act recognize that unnecessary segregation of individuals from the community is a form of discrimination. Both laws and their implementing regulations therefore contain an integration mandate, which requires public entities to administer their services, programs, and activities in the "most integrated setting appropriate" to the needs of qualified individuals with disabilities. In *Olmstead v. L.C.*, the U.S. Supreme Court held that unnecessarily forcing persons with disabilities into nursing homes violates this integration mandate when: (1) the state's reasonable assessment determines that community-based treatment is appropriate; (2) the individual does not oppose community placement; and (3) community placement can be achieved through a reasonable modification of the state's services or programs.

In the years since *Olmstead*, Medicaid beneficiaries have challenged numerous state policies they allege violate the ADA and Rehabilitation Act's integration mandate. Accordingly, federal courts have interpreted the scope of a state's obligation to prevent institutionalization, and, in many cases, enjoined cuts or restrictions to Medicaid community-based LTSS programs that would place beneficiaries at risk of unnecessary institutionalization. (*See* Recent Notable Cases.)

B. Medicaid Act

State participation in Medicaid is voluntary, but if a state decides to participate, it must comply with all the requirements of the federal Medicaid Act and its implementing regulations. In addition to the program-specific guidelines described in Part I, above, the Act imposes generally applicable rules that – unless explicitly waived by CMS – states must follow when administering

their Medicaid programs and services. The following are some of the substantive Medicaid Act requirements most relevant to an individual's ability to access community-based long-term services and supports:

Federal Approval Requirement. To participate in Medicaid, each state's Medicaid State Plan must be approved by the Centers for Medicare and Medicaid Services (CMS). Once a proposed plan is approved, its elements become mandatory and any subsequent changes or amendments must be approved by CMS. Likewise, a state needs CMS approval for any waiver programs it wishes to operate and any changes must be approved by CMS prior to implementation. A state that fails to comply with the terms of its approved plan or waivers violates this federal approval requirement.[1]

Statewideness Requirement. Medicaid law requires that all offered benefits be available to all eligible beneficiaries in the state. When operating programs through a HCBS waiver, a Section 1115 demonstration waiver, or any managed care authority, states can request that CMS waive this requirement in order limit coverage for a service to particular geographic region. (*See* Parts II.B.i-ii, II.D.)

Freedom of Choice Requirement. The Medicaid Act requires that beneficiaries have a choice of qualified service providers. All of the Medicaid managed care authorities, *see* Part II.D, allow states to waive this requirement in order to limit the choices of beneficiaries to those service providers who are part of their health plans' network.

Key Sources of Law

Federal Approval (State Plan):
42 U.S.C. § 1396a(a)
42 C.F.R. §§ 430.12

Statewideness:
42 U.S.C. § 1396a(a)(1)

Freedom of Choice:
42 U.S.C. § 1396a(a)(23)

Reasonable Promptness:
42 U.S.C. § 1396a(a)(8)
42 C.F.R. §§ 435.911, 435.930

Comparability:
42 U.S.C. § 1396a(a)(10)(B)(i)
42 C.F.R. § 440.240

Reasonable Standards:
42 U.S.C. § 1396a(a)(17)
42 C.F.R. § 440.230(c)

Amount, Duration and Scope:
42 C.F.R. § 440.230(b)

Purpose of:

- Medicaid Services:
  42 U.S.C. § 1396-1
- HCBS Waiver Services:
  42 U.S.C. § 1396n(c)(1)
  42 C.F.R. § 441.300

1 Federal approval requirements for waiver programs can be found in their respective authorizing statutes. (*See* Parts I.B, I.D.)

Reasonable Promptness Requirement. Participating states must furnish medical assistance with "reasonable promptness" to all eligible individuals, without delay caused by administrative procedures, and must continue to do so until they are found to be ineligible. States must be prompt in both processing initial Medicaid applications and providing coverage for particular services, including HCBS waiver services. While the reasonable promptness requirement does not prohibit waiting lists for capped HCBS waivers, courts have found that it does prohibit unreasonable delays in processing waiver waiting lists or providing benefits for those already enrolled.

Comparability Requirement. States are obligated to provide comparable services and benefits, *i.e.*, benefits equal in "amount, duration and scope," to all eligible Medicaid beneficiaries with comparable medical needs, regardless of diagnosis. This comparability requirement is violated when some recipients are treated differently than others when each has the same level of need. States can request CMS approval to waive comparability to varying extents when offering services through a range of program vehicles, including HCBS waivers, demonstration waivers, the HCBS state plan option, and any of the managed care authorities. (*See* Parts I.B.i-ii, I.C.iii, and I.D.)

Reasonable Standards Requirement. The Medicaid Act requires states to use "reasonable standards" when determining eligibility for and the extent of the medical assistance provided by a state's Medicaid program – i.e., who can get services and which services are covered. Such standards must be comparable for all Medicaid eligibility groups and consistent with the objectives of Medicaid program. Exclusion of a medically necessary treatment from coverage has been found to run afoul of the reasonable standards requirement. Similarly, courts have found the requirement violated when the clinical eligibility standards for covered services are not reasonably related to need for those services.[2]

Amount, Duration and Scope Requirement. Medicaid services must be provided in sufficient "amount, duration and scope" to "reasonably achieve their purpose." In assessing whether a certain service level is adequate to achieve its intended ends, courts have looked both to the objectives of the specific service at issue and to the objectives of the Medicaid program generally. Thus, to comport with this requirement, community-based services must be available at a level sufficient to reasonably offer recipients the supports they need to avoid institutionalization (their intended purpose as described in the HCBS waiver regulations) and/or to retain capability for independence or self care (the general purpose of the Medicaid Act).

C. Due Process

The Due Process Clause of the Fourteenth Amendment, as interpreted by the U.S. Supreme Court in *Goldberg v. Kelly*, prohibits states from denying, reducing or terminating government benefits without due process of law. Due process includes the right to meaningful notice prior to the termination

2 Medicaid regulations further prohibit states from arbitrarily denying or reducing Medicaid services solely on the basis of diagnosis, type of illness or condition.

of Medicaid benefits, continued benefits pending a pre-termination hearing, and a fair and impartial pre-termination hearing. For notice to be adequate, a state must give the reasons for its action in sufficient detail for the individual to prepare a responsive defense. Age and disability heighten the need for notice to give the specific basis for the denial of benefits.

Federal Medicaid law requires that states administering Medicaid meet the due process standards set forth in *Goldberg v. Kelly* and fleshes out what due process means in a Medicaid context. Specifically, Medicaid beneficiaries have rights to written notice and an opportunity for a hearing before coverage of services, including home and community-based services and supports, can be denied, suspended, reduced or terminated, or if a claim for medical assistance is not acted upon with reasonable promptness. Notices must be mailed at least ten days before the state takes action.

A state Medicaid agency must also grant an opportunity for a hearing when an individual requests one because he or she believes that services have been denied, reduced, suspended, or terminated erroneously. If a current beneficiary requests a hearing before the action takes place, services must be continued at the same level until a decision is made on the appeal.

States are not required to grant an individual hearing if the sole reason for the loss of services is a global change to the Medicaid program (such as the legislative elimination of an optional Medicaid benefit) that affects beneficiaries automatically, *i.e.*, is not based on an individualized factual assessment of a person's status or care needs. Plaintiffs can still challenge automatic cuts on the bases that the cuts should not apply to them, or that they violate substantive Medicaid requirements or other federal laws like the ADA. (*See* Parts II.B, II.A.)

Key Sources of Law

Constitutional Due Process:
U.S. Const., 14th Amendment
Goldberg v. Kelly,
397 U.S. 254 (1970)

Medicaid Act Due Process:
42 U.S.C. § 1396a(a)(3)
42 C.F.R. §§ 431.200-250,
435.912, 435.919

Resources: Legal Protections 101			
	Resource and Citation	**Description**	**Electronic Link**
	A. Disability Rights Laws		
27	CMS, *Olmstead Update No. 4*, State Medicaid Dir. Letter # 01-006 (Jan. 10, 2001)	Federal guidance addressing *Olmstead*-related limits on state discretion in design and operation of 1915(c) HCBS Waivers. Explains that state cannot limit the number of waiver enrollees who receive coverage for a particular service within a waiver and that a waiver's package of services must be sufficient to make it a safe alternative to institutional care.	*downloads.cms.gov/cmsgov/archived-downloads/SMDL/downloads/smd011001a.pdf*
28	NSCLC, *10-Plus Years After the Olmstead Ruling: Progress, Problems and Opportunities* (Sept. 2010)	Provides an overview of the *Olmstead* ruling and the changes that have been made in its wake, and offers recommendations to address the persistent institutional bias in Medicaid LTSS.	*www.nsclc.org/wp-content/uploads/2011/07/NSCLC-Olmstead-Report.pdf*
29	U.S. Department of Justice, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (June 22, 2011)	Technical guide on the ADA's integration mandate and *Olmstead*. Contains Q&A discussing each element of an *Olmstead* claim, types of state conduct that can constitute an *Olmstead* violation (including Medicaid budget cuts), and potential defenses.	*www.ada.gov/olmstead/q&a_olmstead.htm*
30	Bazelon Center for Mental Health Law	Advocacy materials relating to Olmstead and the ADA.	*www.bazelon.org/Where-We-Stand/Community-Integration/ADA-and-People-with-Mental-Disabilities/Other-Resources-about-Civil-Rights-and-the-ADA.aspx*

Resources: Legal Protections 101			
	Resource and Citation	**Description**	**Electronic Link**
		B. Medicaid Act	
31	Disability Rights Education & Defense Fund, Health: Access to Care	Information about accessibility of health care for people with disabilities.	*www.dredf.org/healthcare*
32	National Health Law Program, THE ADVOCATE'S GUIDE TO THE MEDICAID PROGRAM (June 2011)	Comprehensive Medicaid law treatise that covers Medicaid administration, eligibility, and services, drawing extensively from numerous sources: the United States Constitution, the Medicaid Act, the Medicaid regulations, federal guidance documents, and federal and state court case law.	Purchase or subscription only: *healthlaw.org/index.php?option=com_content&view=article&id=110&Itemid=183*
33	Jane Perkins, National Health Law Program, *Q&A: Responding to Medicaid Cutbacks* (Oct. 2011)	Primer discussing when state attempts to eliminate or reduce Medicaid services may run afoul of the Medicaid Act and disability rights laws. Offers an assessment of when litigation might be an appropriate tool to address cutbacks.	*www.healthlaw.org/images/stories/Responding_to_Medicaid%20cuts.10%202011.pdf*
		C. Due Process	
34	Jane Perkins, National Health Law Program, *Issue Brief: Appeal Rights and Medicaid Benefit Reductions* (Dec. 2010)	Medicaid due process primer discussing the appeal rights that apply when Medicaid services are reduced or terminated, with a particular focus on prior authorization and utilization control.	*www.healthlaw.org/images/stories/Issue_Brief_Appeal_Rights_and_Medicaid_Benefit_Reductions.pdf*
35	MaryBeth Musumeci, Kaiser Commission on Medicaid and the Uninsured, *A Guide to the Medicaid Appeals Process* (Mar. 2012)	Guide to Medicaid notice and hearing rights, with a focus on the practical steps of the appeals process. Discusses both traditional state agency hearing processes and Medicaid managed care appeals.	*www.kff.org/medicaid/upload/8287.pdf*

III. Advocacy Issues

The current legal and political landscape presents advocates with both great challenges for maintaining low-income individuals' access to Medicaid-funded long-term services and supports at home, and opportunities to expand such programs in their states. This section identifies key trends in community-based Medicaid LTSS and offers strategies and resources to help advocates address emerging threats and take advantage of new opportunities. First, it examines common budget-driven cuts and outlines strategies state advocates have used to defend access. Second, it offers strategies and resources for use in legislative and administrative advocacy to expand state-wide access to home and community-based services and supports. Finally, it provides an overview of the issues posed by state proposals to shift long-term services and supports into managed care.

A. Defending Community-Based LTSS Programs

As the only discretionary portion of what is most states' second-largest budget line item, optional Medicaid programs like community-based long-term services and supports make an easy target in times of scarcity. States have sought to cut and/or reduce utilization of key community-based LTSS programs in a variety of ways, most of which fall into one of five categories: service reductions or caps, eligibility restrictions, service eliminations, provider rate cuts, and informal barriers to access.

- **Service Reductions**. Benefit reductions or caps place strict limits on the amount of a service an individual can receive.
- **Eligibility Restrictions**. States may also attempt to tighten the rules concerning who can access a particular service. Clinical eligibility restrictions can include everything from requiring increased levels of need in certain activities of daily living to limiting the types of functional needs that can qualify someone for a service. Clinical restrictions might also include new limits on the diagnostic bases of a person's needs. States may also seek to restrict financial eligibility for services, for example by eliminating the special income category for HCBS waiver recipients living in the community. (*See* Part II.B.)
- **Service Eliminations**. Because coverage of community-based long-term services and supports is optional under the Medicaid program, states may also seek to eliminate a service entirely. A state can try to eliminate services like personal care from the state plan Medicaid benefits package. It might also seek to remove a service from waiver coverage, or even, because waivers are themselves optional, completely terminate a waiver that offers community-based LTSS. A state might also seek to move a state plan service into a waiver, so that it can be subject to enrollment caps or other restrictions. (*See* Part I.B.)

- **Provider Rate Cuts**. States may effectively limit availability of Medicaid LTSS by cutting payments to providers, resulting in fewer willing qualified providers and reduced access.
- **Informal Barriers to Access**. In addition to more formal changes to Medicaid LTSS program rules or regulations, states Medicaid agencies may informally adopt policies or practices that result in more service or eligibility denials. For example, a state might alter the process it uses to evaluate eligibility for services or restrictively reinterpret existing eligibility standards. Such policy changes can be explicit, such as in a memo to providers or revised Medicaid program manual, or they may take the form of unpublished instructions to agency staff, or even general pressure to deny services.

Such program changes are subject to applicable legal requirements. (*See* Part II.) For example, reduced access to community-based LTSS that puts beneficiaries at risk of unnecessary institutionalization has the potential to violate the ADA and Rehabilitation Act integration mandates. Service caps have the potential to run afoul of the Medicaid Act's amount, duration and scope. Similarly, imposing more restrictive clinical eligibility criteria may violate the Medicaid Act's reasonable standards or comparability requirements. A state's refusal to provide coverage for such a service when medically necessary may also violate the reasonable standards mandate. And, of course, even otherwise legal terminations or reductions of services must be implemented in a way that is consistent with due process. These legal requirements can therefore offer shields to advocates looking to defend community-based benefit programs from cuts. Stakeholders can target advocacy efforts to a range of audiences:

State-level Advocacy. Community stakeholders should bring potential legal violations as well as policy concerns, including potential costs from greater utilization of institutional LTSS (*see* Part III.B), to the attention of both state legislators and state administrative agencies. Because it is far easier to neutralize a problematic restriction prior to its adoption (particularly in the context of legislative enactments and formal rule-making), advocates should seek to intervene as early in the process as possible. Close monitoring of legislative and agency activity is key to defeating proposals that will have a harmful impact on beneficiaries.

Federal Advocacy. The federal Centers for Medicare and Medicaid Services (CMS) is charged with ensuring state compliance with Medicaid law, and is therefore a critical audience with which to raise concerns about proposed changes that restrict access to Medicaid community-based services and supports. Under the Medicaid federal approval requirement, any changes to Medicaid programs that diverge from the terms of a state's existing state plan or waivers must be submitted to and approved by CMS prior to implementation. Here again, the sooner advocates bring their concerns to CMS, the greater the chance of making a difference. National organizations like NSCLC that routinely work with CMS are happy to help state advocates identify appropriate contacts within CMS.

In addition to CMS, advocates can raise concerns about the legality of restrictions to

Medicaid-funded community-based services and supports with at least two other federal agencies. The U.S. Department of Health and Human Services' (HHS) Office of Civil Rights (OCR) is charged with enforcing the ADA and Rehabilitation Act as applied to recipients of federal HHS funds, including state Medicaid programs. Advocates can contact OCR informally or file official complaints to launch a formal OCR investigation into potential state violations of antidiscrimination laws. The U.S. Department of Justice (DOJ) is the federal government's primary judicial enforcement arm, and can enforce federal laws, including the Medicaid Act, antidiscrimination statutes, and constitutional due process requirements. DOJ can also file statements of interest in cases brought by private individuals.

Litigation. In addition to legislative and administrative advocacy, individuals may be able to challenge cuts and restrictions to Medicaid community-based services and supports in court. (*See* Recent Notable Cases.) In such actions, Medicaid Act, Americans with Disabilities Act, Rehabilitation Act and due process claims can strengthen and complement each other. Medicaid beneficiaries alleging violations of those protections have successfully sued to enjoin community-based LTSS benefit cuts and restrictions in numerous states.

Litigation is, however, a limited and risky tool. Medicaid Act and disability rights protections are not silver bullets. At the end of the day, community-based LTSS programs are still "optional" benefits, and disability rights laws do not require states to alter their Medicaid programs fundamentally. Strong legal arguments should be paired with compelling plaintiffs who can show that they stand to suffer concrete harm to their health and well-being as a result of their state's program changes.

In addition, although the ADA and Rehabilitation Acts contain explicit private rights of action that permit individuals to enforce anti-discrimination protections in court, the Medicaid Act contains no such explicit right to sue. Accordingly, the private enforcement of Medicaid requirements is controversial and some portions of the Act are more easily and directly enforceable than others. Because of the unsettled state of the law in this area, state advocates considering bringing Medicaid Act challenges should consult NSCLC or other national organizations familiar with enforceability issues before proceeding.

B. Expanding Community-Based LTSS

One way to respond to potential budget cuts is to advocate for expansion of HCBS. In most cases, HCBS will cost Medicaid programs less than would equivalent nursing home services. Substituting HCBS for nursing home services can both reduce state expenses and improve the lives of beneficiaries. In addition, states that qualify can take advantage of the substantial federal subsidies offered by new program options like Community First Choice and the Balancing Incentives Payment Program. (*See* Parts II.C.iv-v.)

State officials concerned about costs of expanding access to community-based LTSS often point to the so-called woodwork effect, *i.e.*, that if necessary services are provided

in a community-based setting, individuals who are not currently receiving benefits will supposedly come out of the woodwork to sign up, increasing total costs to the state. According to H. Stephen Kaye's recent research paper in *Health Affairs*, this premise is inaccurate: analyzing 15 years of state expenditure data, the research showed that a gradual transition to HCBS in fact reduces aggregate state LTSS expenditures.

Expenditures for LTSS should be considered together, so that reduced expenditures for institutional LTSS can be considered along with possibly increased expenditures for HCBS.

C. Shifts to Managed LTSS

A growing number of states are proposing to place the responsibility for providing long-term services and supports to seniors and people with disabilities with managed care organizations (MCOs). In theory, when MCOs bear the cost of long-term care, they have a financial incentive to coordinate care better so as keep their beneficiaries healthy and to provide LTSS at home in the community as opposed to in more expensive institutional settings. Thus, integrating LTSS into managed care has the potential to facilitate better care coordination, resulting in better health outcomes, reduced costs, and higher utilization of community-based service options.

On the other hand, without program design that incorporates careful alignment of incentives,[1] meaningful administrative oversight, LTSS-specific evaluation measures and robust consumer protections, MCOs may cut costs simply by denying needed services and/or decreasing provider rates to levels that threaten access for beneficiaries.

Medicaid MCOs have not historically served seniors and people with disabilities and most have limited experience providing long-term services and non-medical supports. Instead, their focus has been on serving the primary and acute care needs of children and families. This lack of experience with LTSS, as well as the ongoing, complex needs of the populations who utilize them, can undercut MCOs' ability to administer those benefits effectively.

Advocates who seek to ensure that beneficiaries in managed LTSS programs have adequate access to services can utilize many of the same tools and strategies described in Part III.A, above.[2] Any proposed LTSS managed care project must comply with specific rules of the relevant managed care authority, as well as the Medicaid rules applicable to all managed care programs, and receive CMS approval prior to

1 When LTSS is provided through managed care, the managed care organization should be responsible for *all* LTSS expenditures, in order to provide a financial incentive for using less expensive community-based services and supports as an alternative for institutional care. (*See* Part III.B.)

2 Even in a managed care context, states retain ultimate responsibility for complying with federal law. Thus, where private enforcement is permitted, beneficiaries can sue the state directly to enforce rights violated by state-contracted MCOs. (*See* Recent Notable Cases.)

implementation. (*See* Part I.F.) (Where the proposal under consideration is a Section 1115 Waiver, advocates should be sure to take advantage of the additional stakeholder engagement opportunities created by the ACA public input rules. (*See* Part I.B.)) Managed LTSS programs are also subject to disability rights laws, due process protections, and any general Medicaid Act requirements not explicitly waived. (*See* Part II.) Finally, because MCOs' specific obligations are dictated by its contract with the state, advocates should closely monitor the development and contents of those contracts even after the contours of a managed LTSS program have been finalized.

Resources: Advocacy Issues			
	Resource and Citation	**Description**	**Electronic Link**
	A. Defending Community-Based LTSS Programs		
36	Community Access National Network, *Medicaid Watch*	Monthly round-up of notable and recent state developments and proposals that affect Medicaid access and eligibility. To sign up for monthly Medicaid Watch updates, email weaids@tiicann.org.	*http://www.adapadvocacyassociation.org/pdf/Medicaid_Watch.pdf*
37	Families USA, *Five Good Reasons Why States Shouldn't Cut Home- and Community-Based Services in Medicaid* (July 2010)	Toolkit outlining arguments advocates can use to fight cuts to Medicaid home and community-based services, including economic and cost-based arguments.	*familiesusa2.org/assets/pdfs/long-term-care/Five-Good-Reasons.pdf*
	Federal Advocacy		
38	Centers for Medicare and Medicaid Services, Organizational Chart (June 18, 2012)	Chart detailing the leadership and organizational structure of CMS. Advocates should target their outreach to the CMS offices that oversees the program about which they are concerned. The Center for Medicaid and CHIP Services is the office responsible for administering Medicaid.	*www.cms.gov/About-CMS/Agency-Information/CMSLeadership/Downloads/CMS_Organizational_Chart.pdf*
39	National Senior Citizens Law Center, *How to File a Language Access Complaint* (Feb. 2011)	Advocate alert giving instruction and guidance on filing a complaint with the Health and Human Services' Office of Civil Rights. Although geared toward language access civil rights complaints, the filing process is the same for federal disability rights complaints.	*www.nsclc.org/wp-content/uploads/2011/07/IHSS-OCR-Complaint.pdf*
40	U.S. Department of Justice, Civil Rights Division, *Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (June 22, 2011)	Technical assistance guide on the ADA's integration mandate as interpreted by Olmstead. In Q&A #18, explains how to file an Olmstead complaint with the Department of Justice.	*www.ada.gov/olmstead/q&a_olmstead.htm*

Resources: Advocacy Issues			
	Resource and Citation	**Description**	**Electronic Link**
		Litigation	
41	Jane Perkins, National Health Law Program, *Q&A: Responding to Medicaid Cutbacks* (Oct. 2011)	Primer discussing when state attempts to eliminate or reduce Medicaid services may run afoul of the Medicaid Act and disability rights laws. Offers an assessment of when litigation might be an appropriate tool to address cutbacks.	*www.healthlaw.org/images/stories/Responding_to_Medicaid%20cuts.10%202011.pdf*
42	Jane Perkins, National Health Law Program, *Update on Private Enforcement of the Medicaid Act Pursuant to 42 U.S.C. § 1983* (Nov. 2011)	Issue brief discussing restrictions on the use of Section 1983 to privately enforce provisions of the Medicaid Act. Includes table on circuit courts rulings on the enforceability of various Medicaid provisions from June 2002 to November 2011.	*www.healthlaw.org/images/stories/IssueBr.1983.nov11.pdf*
43	Rochelle Bobroff, *Section 1983 and Preemption: Alternative Means of Court Access for Safety Net Statutes*, 10 LOYOLA JOURNAL OF PUBLIC INTEREST LAW 27 (2009)	Law review article discussing preemption as an alternative vehicle for enforcing statutory provisions, including Medicaid Act provisions, that are not enforceable through Section 1983.	*www.federalrights.org/Articles/section-1983-and-preemption-alternative-means-of-court-access-for-safety-net-statutes/at_download/attachment*
44	Rochelle Bobroff, *The Courthouse Door Remains Open, But It's Not Over Yet*, American Constitution Society Blog (Feb. 23, 2012)	Blog post examining how the Supreme Court's 2012 Douglas v. Independent Living Center decision affects the viability of using preemption to privately enforce Medicaid Act requirements.	*www.acslaw.org/acsblog/the-courthouse-door-stays-open-but-it%E2%80%99s-not-over-yet*
		B. Expanding Community-Based LTSS	
45	H. Stephen Kaye, *Gradual Rebalancing of Medicaid Long-Term Services and Supports Saves Money and Serves More People, Statistical Model Shows*, 31 HEALTH AFFAIRS 1195 (2012)	Paper presenting statistical model that demonstrates significant cost-savings from rebalancing Medicaid LTSS expenditures toward community-based, rather than institutional care.	*content.healthaffairs.org/content/31/6/1195.full.pdf*

Resources: Advocacy Issues			
	Resource and Citation	**Description**	**Electronic Link**
46	Leslie Hendrickson and Laurel Mildred, *Flexible Accounting for Long-Term Care Services: State Budgeting Practices that Increase Access to Home- and Community-Based Services* (Jan. 2012)	Research paper presenting financial strategies and "flexible accounting" models states have used – and can use – to expand access to community-based LTSS and actually save money in the process, often through reduced utilization of institutional services.	*http://thescanfoundation.org/sites/thescanfoundation.org/files/Mildred_Flexible_Accounting_2.pdf*
47	National Council on Aging, *Advocacy Toolkit: Long-Term Services & Supports*	Online toolkit of resources for advocates working to preserve or expand access to LTSS in their states.	*www.ncoa.org/public-policy-action/advocacy-toolkit/toolkit-for-advocates.html*
48	National Consumer Voice for Quality Long Term Care, *Consumer Perspectives on Quality Homecare* (Sept. 2012)	Report based on interviews with LTSS clients across the country, presenting varied consumer perspectives on quality LTSS at home. Includes personal stories demonstrating the importance of access to quality community-based services.	*www.theconsumervoice.org/consumers-for-quality-care#consumerperspective*
		C. Shifts to Managed LTSS	
49	National Senior Citizens Law Center and Disability Rights Education and Defense Fund, *Long Term Services and Supports: Beneficiary Protections in a Managed Care Environment*	Online toolkit of ideas for LTSS beneficiary protection, which state advocates can use to push for strong protections in managed LTSS programs.	*dualsdemoadvocacy.org/resources/ltss*
50	National Council on Disability, *Analysis and Recommendations for the Implementation of Managed Care in Medicaid and Medicare Programs for People with Disabilities* (Feb. 2012)	White paper offering recommendations on designing Medicaid and Medicare managed care programs to meet the needs of individuals living with disabilities.	*http://www.ncd.gov/publications/2012/CMSFebruary272012/*
51	MaryBeth Musumeci, Kaiser Commission on Medicaid and the Uninsured, *A Guide to the Medicaid Appeals Process* 14-21 (March 2012)	Guide to Medicaid notice and hearing rights, with a focus on the practical steps of the appeals process. Discussion of Medicaid managed care appeals processes begins on p. 14.	*www.kff.org/medicaid/upload/8287.pdf*

Conclusion

The combination of increased demand for long-term services and supports, the new program options available to states for offering such Medicaid-funded services at home, and intense pressure on state budgets have set the stage for the transformation of Medicaid LTSS. Consumer advocates have a critical role to play in this process: only their active participation can ensure that the LTSS programs that emerge will increase, not diminish, access to critical community-based care options for the elderly and those with disabilities.

Recent Notable Cases		
Case	**Issue**	**Notable Results**
Brantley v. Maxwell-Jolly 656 F.Supp.2d 1161 (N.D. Cal. 2009)	Challenge to cuts to California's Medicaid state plan Adult Day Health Care benefit (suit continued in *Cota*, below). Across-the-board reduction of maximum service days from 5 to 3 days per week.	District Court found likely violations of ADA and Rehabilitation Act integration mandate. Beneficiaries faced serious risk of institutionalization and alternative services to help them remain in the community were not identified or in place.
Bryson v. Shumway 308 F.3d 79 (1st Cir. 2002)	Challenge to New Hampshire's administration of waiting lists for slots in HCBS 1915(c) waiver for adults with brain injuries, which had capped enrollment. State maintained waiting list but apparently declined to fill some approved slots.	First Circuit held that Medicaid's reasonable promptness requirement applies to applicants for HCBS waiver programs. Although states can maintain waiver waiting lists, failure to process and fill waiver slots while eligible individuals are waiting to enroll has the potential to violate the reasonable promptness guarantee. Remanded for further factual inquiry into the nature of the delay.
Cota v. Maxwell-Jolly 688 F.Supp.2d 980 (N.D. Cal. 2010)	Challenge to cuts to California's Medicaid State Plan Adult Day Health Care (ADHC) benefit (continuation of lawsuit in *Brantley*, above). State imposed new, more restrictive eligibility criteria, including fewer qualifying functional impairments.	District Court found likelihood of success on ADA/*Olmstead*, Medicaid Act and due process claims. Current plan of care documents indicate need for ADHC to avoid institutionalization. New eligibility criteria imposed reductions based on arbitrary criteria unrelated to relative need for the service and likely violated Medicaid Act reasonable standards and comparability requirements. State cannot disclaim responsibility for issuing notices when delegating responsibility for assessment to providers.

1 This table offers summaries of some recent, noteworthy court challenges to community-based LTSS program cuts, as well as other cases that bear on advocates' ability to defend against restricted access to such programs in the future. This list is not exhaustive. Instead, it is intended to provide a sense of the kinds of Medicaid LTSS policies advocates have challenged through litigation, and how courts have decided those cases.

Recent Notable Cases		
Case	**Issue**	**Notable Results**
Crabtree v. Goetz 2008 WL 5330506 (M.D. Tenn. Dec. 19, 2008)	Tennessee cut private duty nursing, home health care and home health aide care services available through TennCare, a Medicaid managed care program operating under a Section 1115 waiver. Restrictions included capping combined home services at 35 hours per week. Services provided through managed care organizations contracted with the state.	Based on physician and health care provider evidence, and state's own prior determination of medical necessity, Court concluded that state's home service cuts would force waiver beneficiaries into nursing homes and likely violate the ADA.
Grier v. Goetz 402 F. Supp. 2d 876 (M.D. Tenn. 2005)	Tennessee sought to modify an earlier consent decree to allow limit on prescription drug coverage to 5 prescriptions per month for enrollees in Medicaid managed care programs operating under a Section 1115 Waiver. A "shortlist" of drugs required to treat specific medical conditions was exempt from monthly limit.	The District Court determined the prescription cap, coupled with the "shortlist," did not violate Medicaid's amount, duration and scope requirement. It gave "substantial deference" to CMS approval of cap. The court found that, although the policy might result in some denial for medically necessary treatment, the evidence did not show that it would do so for most TennCare enrollees. Modification of consent decree premitted.
Hiltibran v. Levy 793 F. Supp. 2d 1108 (W.D. Mo. 2011)	Missouri refused to provide Medicaid state plan coverage for incontinence briefs (disposable diapers) for beneficiaries aged 21+ residing in the community, despite physician documentation of ongoing medical need. Medicaid per diem for adults residing in institutions, such as nursing homes, could be used to cover incontinence supplies.	Court held that Missouri's refusal to cover medically necessary adult incontinence supplies by arbitrarily denoting them "personal hygiene items" violated Medicaid's reasonable standards requirement. Missouri's policies also violated ADA and Rehab Act integration mandates by requiring institutionalization in order to get coverage for medically needed supplies.

Recent Notable Cases		
Case	**Issue**	**Notable Results**
M.R. v. Dreyfus 767 F. Supp. 2d 1149 (W.D. Wash. 2011) **Note: Reversed on appeal (see below)**	Challenge brought against cuts to Washington State's state plan personal care service benefit. New state law imposed an across-the-board reduction in the Medicaid state plan personal care service hours.	District Court denied preliminary injunction, finding that cuts in hours would not deny needed services or put beneficiaries at serious risk of institutionalization, because services had previously been allocated based on state budget constraints, not minimum levels of need. No likelihood of success on claims under the ADA integration mandate or Medicaid reasonable standards, amount, duration, and scope comparability, freedom of choice, or federal approval requirements. Rejected beneficiaries' due process claim on the basis that no notice was needed when service cuts were automatic.
M.R. v. Dreyfus 663 F.3d 1100 (9th Cir. 2011)	Appeal of district court decision (*see* above) approving across-the-board reductions in service hours available under Washington State's state plan personal care service.	Ninth Circuit held that serious risk of institutionalization is sufficient for *Olmstead* claim. Budget concerns alone not sufficient for a state to make a make fundamental alteration defense. Reversed district court and remanded for entry of a preliminary injunction.
Newton-Nations v. Betlach 660 F.3d 370 (9th Cir. 2011)	CMS granted Arizona Section 1115a demonstration proposal, which waived Medicaid cost-sharing restrictions and increased copayments, so providers could decline to serve those who could not afford to pay. CMS granted Arizona's request for waiver and approved the demonstration.	Reversing in part denial of summary judgement, Ninth Circuit held that CMS's approval of co-payment increases as a purely cost-saving measure, with no experimental value or potential to promote the goals of the Medicaid Act, was arbitrary and capricious and exceeded CMS's authority to approve demonstration waivers under Section 1115a.

Recent Notable Cases		
Case	**Issue**	**Notable Results**
Pashby v. Cansler 279 F.R.D. 347 (E.D.N.C. 2011)	North Carolina altered Medicaid state plan personal care services (PCS) eligibility rules, increasing the level of functional impairment needed to qualify. Beneficiaries residing in institutions or adult care homes are not subject to same heightened requirements for PCS coverage.	District Court preliminarily enjoined new PCS eligibility rules. Found that application of stricter PCS eligibility criteria for those living in the community likely violates Medicaid comparability requirement. Found likely violation of ADA and Rehab Act integration mandates based on risk of institutionalization for beneficiaries no longer eligible for PCS, and likely due process violation because notices failed to provide detailed reasons for terminations. "Brutal need" from loss of PCS heightened state's obligation to provide detailed notice.
Pitts v. Greenstein 2011 WL 1897552 (M.D. La. May 18, 2011)	Louisiana cut maximum weekly service hours for state plan personal care from 56 to 42 and then to 32. State waiver programs offer supplemental hours, but have age/geographic restrictions and long waiting lists.	District Court denied state's summary judgment request, finding that change put those who need more than 32 hours of assistance per week at increased risk for institutionalization in violation of the ADA and Rehab Act integration mandates. Genuine factual questions exist as to whether maintaining higher cap on hours is a fundamental alteration or a reasonable modification.

Recent Notable Cases		
Case	**Issue**	**Notable Results**
V.L. v. Wagner 669 F.Supp.2d 1106 (N.D. Cal. 2009)	Challenge to cuts in California's Medicaid state plan in-home supportive services benefit. State sought to cut services using eligibility tools that rank and score beneficiaries based on the type and number of their functional impairments. State also sought to eliminate assistance with shopping and meal preparation as covered tasks.	District Court found likelihood of success on ADA, Medicaid Act and due process claims. Service reductions put beneficiaries at risk of institutionalization because previously awarded hours were based on the level of assistance needed to remain safely at home. Elimination of shopping and meal preparation services likely violates Medicaid sufficiency requirement. New eligibility tool would discriminate against those with mental and cognitive impairments, violating Medicaid Act comparability and reasonable standards requirements. Notice likely inadequate because not sufficiently calibrated to recipients with mental disabilities and limited ability to read English.

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