



**National Senior Citizens Law Center**

PROTECTING THE RIGHTS OF LOW-INCOME OLDER ADULTS

SPECIAL REPORT

# 10-Plus Years After the *Olmstead* Ruling

## PROGRESS, PROBLEMS, AND OPPORTUNITIES

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# Executive Summary

Inside and outside government, there is now a widely held view that home and community-based services (HCBS) can better maintain the independence and dignity of persons needing long-term services and supports (LTSS). Consistent with this understanding, statistics show a significant percentage increase in older persons able to receive LTSS outside of nursing homes. Nonetheless, unnecessary institutionalization is still a routine problem for too many older adults and people with disabilities, especially those with lower incomes.

## **Olmstead Ruling and Effects**

In 1999, the United States Supreme Court ruled in *Olmstead v. L.C.* that unnecessary institutionalization of people with disabilities is a type of discrimination prohibited by the Americans with Disabilities Act (ADA). A state government that operates its programs in a way that unnecessarily forces persons with disabilities to move into nursing homes or other institutions violates the ADA. Under the ADA, a state government is not required to make a “fundamental alteration” to a program to accommodate the needs of a person with a disability—but it can be required to make a “reasonable modification.”

Nationally, the *Olmstead* decision has had two principal effects. First, the case confirmed that a state could be sued if its programs lead to unnecessary institutionalization. Second, the *Olmstead* decision and its reasoning have become accepted in the community, particularly throughout the network of persons providing aging services. Policymakers, stakeholders, and many consumers are familiar with *Olmstead* and understand the core of its ruling—that people with disabilities have a right not to be relegated to nursing homes, psychiatric hospitals, and like institutions.

## **New Efforts to Increase HCBS**

Motivated in part by *Olmstead*, and by the *Olmstead*-consistent philosophy of maximizing independence, both Congress and federal agencies have acted to increase access to HCBS for persons in need of LTSS. For example, Congress in the Deficit Reduction Act of 2005 added several HCBS programs. These include the Money Follows the Person (MFP) program to fund transitions out of nursing facilities, and the HCBS State Plan Benefit program to allow state Medicaid programs to more easily offer packages of HCBS. In the 2006 reauthorization of the Older Americans Act, Congress directed the Administration on Aging (AoA) and state aging agencies to reshape the LTSS delivery system to provide more HCBS.

Most recently, the Patient Protection and Affordable Care Act of 2010 (PPACA, Pub. L. No. 111-148) expanded the MFP program and the HCBS State Plan Benefit program. The PPACA also initiated a Medicaid State Balancing Incentive Payments Program that will give states financial incentives to increase the percentage of persons who receive LTSS through HCBS, and it added a new service—the “Community First Choice Option”—to Medicaid’s menu of benefits. Additionally, the PPACA required that Medicaid HCBS programs offer protections against spousal impoverishment, although the requirement applies only during the five-year period beginning in 2014.

## **Federal Court Decisions**

Further, federal court decisions have played a role in enunciating states’ responsibilities under *Olmstead*. Federal courts have ruled consistently that the ADA’s protections apply to persons living in the community, not just to persons already institutionalized. In a recent case, for



example, a federal judge relied on the ADA and *Olmstead* in preventing California from imposing cuts on its Adult Day Health Care program.<sup>1</sup>

Courts also have ruled that a state’s modification of financial or clinical eligibility standards is not necessarily a “fundamental alteration,” and thus ADA litigation can be used to seek loosening of such eligibility standards. Likewise, additional expense to the state does not necessarily constitute a fundamental alteration, so a state’s claim of inadequate financial resources is not an automatic defense.

### Current Status: Bias Toward Institutionalization

Despite this progress, the availability of LTSS for older persons remains slanted unduly toward institutionalization. In describing the status quo in the PPACA, Congress stated:

Despite the ... *Olmstead* decision, the long-term care provided to our Nation’s elderly and disabled has not improved. In fact, for many, it has gotten far worse. ... Although every State has chosen to provide certain services under [Medicaid] home and community-based waivers, these services are unevenly available within and across States, and reach a small percentage of eligible individuals.<sup>2</sup>

Indeed, limitations in the current system are largely attributable to Medicaid’s bias (intended or not) toward institutions over HCBS. While Medicaid is the single greatest source of coverage for HCBS, Medicaid’s statutory framework generally makes coverage for institutional care easier for people to attain.

<sup>1</sup> Cota v. Maxwell-Jolly, 688 F. Supp. 2d 980 (N.D. Cal. 2010).

<sup>2</sup> Pub. L. No. 111-148, § 2406.

### Waivers

The primary reason for this bias is the differences in Medicaid between nursing home coverage and HCBS waiver coverage. Nursing home care is an entitlement under federal Medicaid law: it must be made available to any person who satisfies the relevant financial and clinical eligibility standards. By contrast, in most cases, HCBS is provided through a Medicaid waiver. Waivers have limited enrollment, so that a person may be denied coverage despite meeting financial and clinical eligibility standards. Also, waivers operate under expenditure caps, so in some instances coverage for HCBS can be denied due to excess cost. In many cases, nursing home income eligibility rules are more generous than the rules governing HCBS waivers.

Medicaid beneficiaries can access HCBS to a certain extent outside of waivers. However, non-waiver coverage is subject to more restrictive financial eligibility standards. Additionally, all Medicaid coverage for HCBS is limited by the fact that it does not include financial support for room and board, whereas room and board costs are included in Medicaid’s payment for nursing home care. Furthermore, because of the optional nature of almost all Medicaid HCBS coverage, state legislators frequently look to Medicaid HCBS programs for cuts in times of budgetary constraints.

Other problems limit the effectiveness or quality of HCBS programs. HCBS waivers have limited quality of care standards, particularly when compared to the extensive federal standards applicable to nursing home care. Also, Medicaid waiver funding is currently used for services provided in assisted living facilities, with little assurance that the assisted living facilities truly have a community-based character. In a worst-case scenario, the HCBS provided in an assisted living facility may be just as institutional in nature as those provided in nursing homes.



## Limits of Litigation

ADA litigation also is limited in many ways. Most obviously, the unavailability of HCBS for a person or persons does not necessarily constitute an ADA violation. In addition, even if an ADA violation is found, a state is not required to take action if the requested action would constitute a “fundamental alteration” of a state’s program. A state is more likely to be deemed in compliance with *Olmstead* if it has a comprehensive plan and a waiting list that moves at a reasonable pace. A state may use an “*Olmstead* plan” to defend litigation as much as for integration.

## Recommendations

Based on progress made to date, along with remaining problems and limitations, this report recommends specific steps that federal and state governments should take to reduce the incidence of unnecessary institutionalization.

### End Medicaid’s Bias Toward Institutional Care

- Make Medicaid coverage for home and community-based services (HCBS) an entitlement
- Harmonize eligibility standards for coverage of nursing home care and HCBS
- Permanently mandate Medicaid spousal impoverishment protections for spouses of HCBS enrollees, and make those protections available immediately
- Establish income allocations sufficient to allow Medicaid enrollees to afford room and board expenses

### Improve Quality of Care

- Ensure adequate quality of care in HCBS settings
- Ensure community-based character of settings where HCBS are provided

### Enhance State Commitment

- Encourage states to participate in expanded HCBS options
- Ensure federal government establishes compliance standards for states receiving federal money based on promises to advance community-based care

### Improve Coordination of Programs and Services

- Emphasize HCBS in 2011 reauthorization of Older Americans Act
- Develop consistent funding sources for Aging and Disability Resource Centers (ADRCs)
- Coordinate federal programs from the Centers for Medicare & Medicaid Services (CMS), the Department of Housing and Urban Development (HUD), and the Administration on Aging (AoA)

The 11 years since the *Olmstead* ruling have brought much progress, but challenges remain. To realize an LTSS system that is less reliant on institutionalization, the federal and state governments should implement the above recommendations. Increased use of HCBS would bring more dignity and independence to the lives of persons requiring LTSS, and has great potential to reduce federal and state costs over the long term.



# 10-Plus Years After the *Olmstead* Ruling

PROGRESS, PROBLEMS, AND OPPORTUNITIES

## INTRODUCTION: The Supreme Court's *Olmstead* Ruling

In 1999, the United States Supreme Court ruled in *Olmstead v. L.C.*<sup>3</sup> that unnecessary institutionalization of people with disabilities is a type of discrimination prohibited by the Americans with Disabilities Act (ADA). The ruling has been extremely prominent in both legal and non-legal circles. For many, “*Olmstead*” has become shorthand for the principle that institutionalization should be a last resort for persons who need long-term services and supports (LTSS).

*Olmstead* was filed in 1995, five years after the ADA’s passage, by two women who were confined in a Georgia state psychiatric hospital. They claimed in the lawsuit that the state’s failure to provide them a community-based alternative to institutionalization was a violation of the ADA. Although the state’s professionals agreed that the women would be able to live in the community with proper supportive services, Georgia community mental health officials claimed they could not provide those services. The state in turn defended the lawsuit by

claiming that the supportive services requested by the plaintiffs were not required by the ADA.

In its ruling, the Supreme Court interpreted the ADA’s Title II, which applies to state and local governments. The relevant statute broadly states that a disability should not cause a person to be excluded from public services, or subject that person to discrimination by state or local governments.<sup>4</sup>

The question for the Court was whether the plaintiffs had been discriminated against by the state’s failure to provide them with a non-institutional alternative to the psychiatric hospital. In interpreting the ADA, the Court relied heavily on a regulation promulgated by the U.S. Department of Justice to implement the ADA. One provision—commonly referred to as the ADA’s “integration mandate”—requires a state or local government to “administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”<sup>5</sup> Under

<sup>3</sup> 527 U.S. 581 (1999).

<sup>4</sup> 42 U.S.C. § 12132.

<sup>5</sup> 28 C.F.R. § 35.130(d).



a second provision of the regulation, a state or local government must “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability.” The state is excused from making a modification if it “would fundamentally alter the nature of the service, program, or activity.”<sup>6</sup>

In its analysis, the Court first found that that unjustified institutionalization of people with disabilities is indeed a type of discrimination prohibited by Title II. As explained by the Court, unnecessary institutionalization “perpetuates unwarranted assumptions” that people with disabilities “are incapable or unworthy of participating in community life.”<sup>7</sup> Also, being confined to an institution “severely diminishes ... everyday life activities,” including family and social relationships, work options, education, and cultural enrichment.<sup>8</sup> Thus, the plaintiffs had suffered discrimination.

The remaining issue was whether the state’s funding of the necessary community-based services would constitute a “reasonable modification” required by the ADA or, on the other hand, a “fundamental alteration” beyond the law’s mandate. The Court noted that reasonableness was to be based on the state’s ability to function—*not* on only the cost to provide necessary services to the named plaintiffs. Rather, deciding if modifications were reasonable meant considering how across-the-board modifications to state programs would affect the state’s ability to function, including its ability to provide necessary services to other populations in need. The Court provided an example:

If ... the State were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated, the reasonable-modifications standard would be met.<sup>9</sup>

The Supreme Court did not rule on whether the modifications requested of Georgia were reasonable or not. Instead, the Court sent the case back to be reconsidered by the lower courts under the standards enunciated by the Supreme Court. This remand ultimately resulted in a settlement the following year when the state agreed to provide additional community-based services.

Nationally, the *Olmstead* decision has had two principal effects. First, the case confirmed a state’s obligation under the ADA to operate public programs in a way that does not unnecessarily institutionalize persons with disabilities. Relying on the *Olmstead* decision, other persons with disabilities have filed litigation to seek reasonable modifications to a state’s policies. Second, the *Olmstead* decision and its reasoning have become accepted in the community, particularly throughout the network of aging services providers. Policymakers, stakeholders, and many consumers are familiar with *Olmstead* and understand the core of its ruling—that people with disabilities have a right not to be relegated to nursing homes, psychiatric hospitals, and like institutions.

<sup>6</sup> 28 C.F.R. § 35.130(b)(7).

<sup>7</sup> 527 U.S. at 600.

<sup>8</sup> 527 U.S. at 601.

<sup>9</sup> 527 U.S. at 605-606.



# PROGRESS:

## The Eleven Years Following *Olmstead*

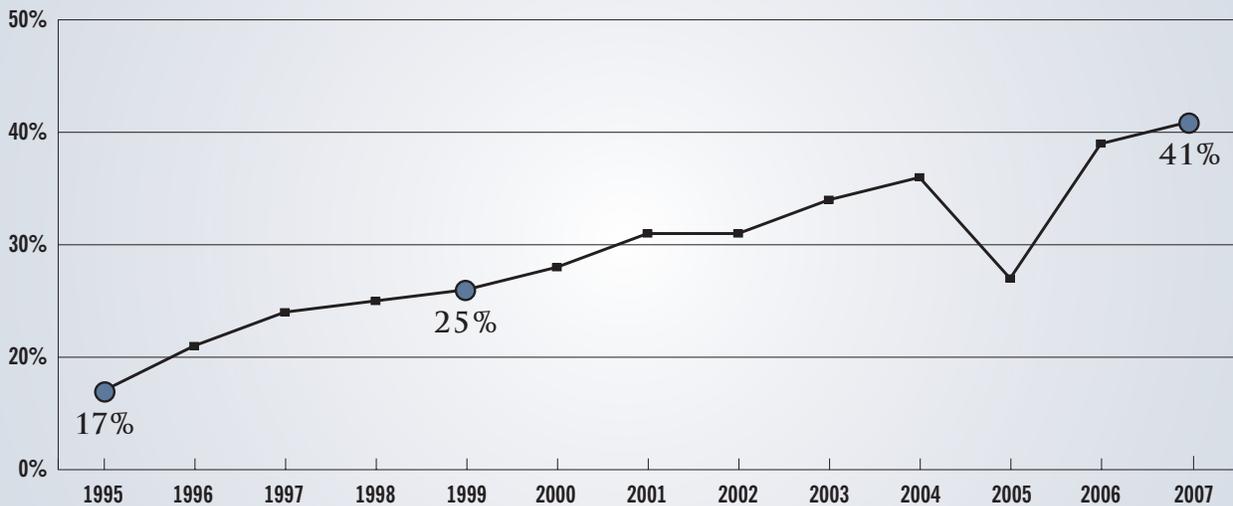
### Overview

The *Olmstead* plaintiffs were enrolled in the Medicaid program, the nation’s single largest purchaser of long-term services and supports (LTSS) then and ever since. In 1999, the year of the *Olmstead* decision, approximately 25% of Medicaid spending for LTSS paid for home and community-based services (HCBS) for older adults and persons with disabilities. By 2007, this percentage had risen to 41%. Between 1999 and 2004, there was a 44% increase in the number of persons receiving Medicaid coverage for HCBS.<sup>10</sup> (See Chart A.)

These increases were not coincidental. Motivated in part by *Olmstead*, both Congress and federal agencies have authorized a number of new programs designed to connect persons who need LTSS to community-based services.

Some of the advances were in direct response to *Olmstead*. Shortly after the decision, the federal government sent “*Olmstead* letters” to states, advising the states how they could better utilize their Medicaid programs to meet the *Olmstead* mandates.

**Chart A: Percentage of Medicaid Long Term Care Spending Going to HCBS, 1995–2007 (All Medicaid Beneficiaries)**



Source: Thomson Reuters (formerly Medstat) (2007)

<sup>10</sup> Enid Kassner et al., AARP Public Policy Institute, *A Balancing Act: State Long-Term Care Reform 5* (2008), available at [http://assets.aarp.org/rgcenter/il/2008\\_10\\_ltc.pdf](http://assets.aarp.org/rgcenter/il/2008_10_ltc.pdf).



Other new federal initiatives were not driven exclusively or even principally by *Olmstead*, but by the *Olmstead*-consistent philosophy of maximizing independence. For example, the 2006 reauthorization of the Older Americans Act added new mandates for the Administration on Aging (AoA) and state agencies to reshape the LTSS delivery system.<sup>11</sup> It also expanded the preexisting responsibility of the aging services network—comprised of service providers, particularly those funded through the AoA—to help older persons avoid “unnecessary institutionalization.”

The Deficit Reduction Act of 2005 added the Money Follows the Person (MFP) program and addressed specific problems hampering growth of HCBS.<sup>12</sup> In 2010, the Patient Protection and Affordable Care Act of 2010 (PPACA, Pub. L. No. 111-148) included a number of provisions to expand Medicaid’s coverage of HCBS and further shift Medicaid spending away from institutional care.

Further, federal court decisions have played a role in enunciating states’ responsibilities and enhancing protections for consumers. For instance, several rulings have established that states under the ADA must assist persons to avoid institutionalization in the first place.

Overall, post-*Olmstead* developments have improved consumer access to HCBS. However, unnecessary institutionalization is still a routine problem for too many older adults and people with disabilities, especially those with lower incomes.

## Early Federal Initiatives

### *Olmstead* Letters to State Medicaid Agencies

Soon after the *Olmstead* ruling, the Health Care Financing Administration (HCFA) stepped in. HCFA, the federal agency operating the Medicare and Medicaid programs at that time, issued five “*Olmstead* letters” to state Medicaid agencies to advise them of the decision’s relevance to state Medicaid operations.<sup>13</sup> The agency’s letters provided recommendations to states on facilitating access to HCBS, and the letters clarified federal Medicaid policy to support the states’ efforts. Later letters issued by the agency, even though not formally entitled “*Olmstead* letters,” continued to communicate with states about ways in which Medicaid programs could advance HCBS.

Highlights of these letters are set forth in Table B.<sup>14</sup> In general terms, *Olmstead* Letters #1 and #2, issued in 2000, addressed the *Olmstead* decision specifically, with a focus on the ruling’s requirement that a state have a plan for reducing unnecessary institutionalization. Topics for later letters included home health services and case management services (*Olmstead* Letter #3), Medicaid waivers (*Olmstead* Letter #4), and income allowances (*Olmstead* Letter #5). Letters in 2002 and 2003 explained that Medicaid can be used to cover medical equipment, and transition expenses such as security deposits and moving expenses. Most recently, in a 2010 letter, the agency reaffirmed its available technical support for state initiatives to expand HCBS.

<sup>11</sup> Pub. L. No. 109-365.

<sup>12</sup> Pub. L. No. 109-171.

<sup>13</sup> HCFA was renamed the Centers for Medicare & Medicaid Services (CMS) in 2001. References to “the agency” include either or both, as appropriate.

<sup>14</sup> Each of these letters is available at CMS’s on-line compilation of State Medicaid Director Letters, [www.cms.gov/SMDL/SMDL](http://www.cms.gov/SMDL/SMDL).



**Table B: Federal Letters to States**

Date	Letter	Contents
Jan. 14, 2000	<i>Olmstead</i> Letter #1	<ul style="list-style-type: none"> <li>■ Agency provides principles for state development of “<i>Olmstead</i> plan,” and “strongly recommend[s]” that states adopt these principles, as principles will be used by HHS Office for Civil Rights in investigating ADA compliance.</li> </ul> <p>Also says that:</p> <ul style="list-style-type: none"> <li>■ States should provide opportunities for interested persons to participate in plan development.</li> <li>■ States should identify and evaluate existing HCBS. Federal government will review federal Medicaid policies to facilitate states’ compliance with <i>Olmstead</i>.</li> </ul>
July 25, 2000	<i>Olmstead</i> Letter #2	<ul style="list-style-type: none"> <li>■ Agency answers questions from states regarding <i>Olmstead</i> Letter #1.</li> </ul>
July 25, 2000	<i>Olmstead</i> Letter #3	<ul style="list-style-type: none"> <li>■ States must not condition Medicaid home health services on person being “homebound.”</li> <li>■ States may make retainer payments to personal care provider when HCBS waiver enrollee is temporarily institutionalized, in order to ensure consistent income for care provider.</li> <li>■ States can cover targeted case management services provided up to 180 days before transition of nursing home resident to community, and home modifications made while a person is living in institution but preparing to transition to community.</li> </ul>
Jan. 10, 2001	<i>Olmstead</i> Letter #4 (State Medicaid Dir. Letter #01-006)	<ul style="list-style-type: none"> <li>■ States cannot limit number of HCBS waiver enrollees who receive coverage for particular service within waiver.</li> <li>■ States must assure that waiver’s package of services is sufficient to make it a safe alternative to institutional care.</li> <li>■ Any reduction of state’s enrollment limit must not negatively impact any person already receiving services.</li> </ul>



**Table B: Federal Letters to States (continued)**

Date	Letter	Contents
Jan. 10, 2001	<i>Olmstead</i> Letter #5 (State Medicaid Dir. Letter #01-007)	<ul style="list-style-type: none"> <li>■ States can use income deductions to make medically needy Medicaid eligibility more accessible.<sup>15</sup></li> </ul>
May 9, 2002	State Medicaid Dir. Letter #02-008	<ul style="list-style-type: none"> <li>■ States can use HCBS waivers to cover one-time expenses incurred by persons transferring from institutions to community. Such expenses could include security deposits for housing, deposits for utility services, or moving, cleaning, or pest eradication expenses.</li> </ul>
July 14, 2003	State Medicaid Dir. Letter #03-006	<ul style="list-style-type: none"> <li>■ States can cover medical equipment for persons transferring from institutions to community, through Medicaid home health services, HCBS waivers, and other means.</li> </ul>
May 20, 2010	State Medicaid Dir. Letter # 10-008	<ul style="list-style-type: none"> <li>■ CMS provides technical assistance so that state Medicaid programs can be designed and operated in ways that make living in community more feasible.</li> <li>■ HHS has partnered with HUD to make housing more accessible for low-income persons with disabilities and, through Community Living Initiative, CMS and other federal agencies are working to increase ability of persons with disabilities to live in community.</li> </ul>

<sup>15</sup> Through a medically needy program, if a person has too much income to be eligible through another eligibility category, she can become eligible by spending down income on health care expenses to the medically needy income level (MNIL). The MNIL in most states is very low, so spending down to the MNIL leaves the person with insufficient income to cover room, board, and other expenses. With an income deduction, however, she can retain additional income.



## Home and Community-Based Services Waivers (Section 1915(c) Waivers)

An HCBS waiver is a Medicaid option that allows a state to provide a package of HCBS services to persons who have care needs that would qualify them for nursing home services. The theory driving HCBS waivers is that the state Medicaid program can reduce its expense, and beneficiaries can receive the care they need in a less-institutional environment. What is waived are federal Medicaid rules that otherwise require that services be available equally to all qualified persons. Thus, waiver services may be limited to a certain number of persons annually, persons with a particular diagnosis, and/or those from a certain part of the state.

HCBS waivers also are called Section 1915(c) waivers, as the primary and most often used authority for these waivers is contained in Section 1915(c) of the Social Security Act.

## Real Choice Systems Change Grants for Community Living

Beginning in 2000, Congress appropriated money for Real Choice Systems Change Grants for Community Living. These grants, administered by the Centers for Medicare & Medicaid Services (CMS), were made to individual states to improve the states' infrastructure for providing community-based care.<sup>16</sup> The Real Choice program, however, was not explicitly mandated by *Olmstead*, although undoubtedly the program has assisted

<sup>16</sup> H.R. Rep. No. 106-1033, at 150 (2000).

states in reducing the incidence of unnecessary institutionalization.

The initial 2001 and 2002 Real Choice grants (about \$1.3 million each and awarded to nearly every state) included initiatives to provide consumer-directed care, involve consumers more in the planning and evaluation of services, and create single-point-of-entry systems in which persons needing LTSS could initiate access to all necessary services through one state agency.<sup>17</sup> The 2003 and 2004 grants included awards to 28 states to improve quality assurance. Beginning in 2005, fewer grants were awarded, but the grant award amounts were larger, to promote more comprehensive systems change.<sup>18</sup>

Overall, between fiscal years 2001 and 2009, CMS awarded 352 Real Choice grants in 39 categories for a total of approximately \$284 million. The program now has been phased out, and CMS claims that in many states it has led to “enduring improvements that promote a more balanced long term care system,” particularly in those states that had received multiple grants.<sup>19</sup>

## Deficit Reduction Act of 2005

### Money Follows the Person (MFP) Program

The MFP program was authorized by the Deficit Reduction Act of 2005 (DRA). Through MFP, Congress authorized payment of \$1.7 billion for state efforts to transition Medicaid-enrolled nursing home residents to the community. In practice, the Medicaid money “follows” the Medicaid beneficiary from a nursing home to a community-based setting. MFP assistance initially was available only to persons who had resided in a nursing home for at least 180 days;

<sup>17</sup> Center for Personal Assistance Services, UCSEF, Federal Systems Change Grants to States and Territories: 2001-2005, <http://www.pascenter.org/systemschange/index.php>.

<sup>18</sup> CMS, *Real Choice Systems Change*, available at [http://www.cms.gov/CommunityServices/30\\_RCSC.asp](http://www.cms.gov/CommunityServices/30_RCSC.asp).

<sup>19</sup> *Id.*



this prerequisite was reduced to 90 days by the PPACA, as discussed further below.

From 2006 to 2011, for the first 12 months after each Medicaid enrollee transitioned, states receive an increased federal reimbursement rate for the community services they provide that enrollee. Through a competitive process, CMS made MFP awards to 30 states and the District of Columbia, with the expectation that approximately 37,000 nursing home residents would be transitioned from 2006 through 2011.

### **HCBS State Plan Benefit (Section 1915(i) Benefit)**

In the DRA, Congress additionally authorized the Medicaid HCBS State Plan Benefit, also known as the “Section 1915(i)” Benefit.<sup>20</sup> This benefit permits states to make packages of HCBS available to Medicaid beneficiaries who are not enrolled in waivers. Some advantages of this benefit are that its clinical eligibility standard must be less restrictive than the standard used for nursing home services and HCBS waivers, and that a state is not limited in the amount it spends on the State Plan Benefit. As the HCBS State Plan Benefit originally was set forth in the DRA, financial eligibility was limited by the requirement that recipients always have incomes no more than 150% of the Federal Poverty Level (\$1,355 in 2010). Also, states could limit enrollment, and only certain specified services could be included in the package of services. These limitations were eliminated or changed in the PPACA, as discussed below.

### **Self-Directed Personal Care Option**

The DRA also provided states the authority to more easily incorporate consumer self-direction into Medicaid-funded HCBS.<sup>21</sup> Self-direction refers to the consumer controlling the

services, such as choosing the service provider, instructing the provider on when services will be administered, or establishing the provider’s pay rate. Self-direction advances one of the ADA’s most basic principles—the empowerment of the person, recognizing that she has unique needs.

The concept of self-directed services was first given serious consideration in the 1990s when the Robert Wood Johnson Foundation began funding programs to foster more consumer direction. Most prominent were the “Cash and Counseling” programs started in three states in 1996 and extended to other states in 2004.

In the DRA, Congress provided states the option of “self-directed personal assistance services.” No waiver is required. Enrollees are permitted to use the service budget to hire, fire, supervise, and manage service providers, who may be family members. States are permitted to limit the number of Medicaid enrollees who self-direct their care, and to restrict the allowance to Medicaid enrollees living in particular areas of the state.

### **Older Americans Act: 2006 Reauthorization and AOA Initiatives**

Like the Medicaid program, the Older Americans Act of 1965 and its many reauthorizations (OAA) supported programs to provide community-based services even before the *Olmstead* decision was issued. The OAA’s original declaration of purposes established principles of independence and integration that both the ADA and the *Olmstead* decision later mirrored.<sup>22</sup> OAA amendments in 1975 required states to provide services that “assist older persons in leading independent lives and avoiding unnecessary institutionalization.”<sup>23</sup> The OAA’s 2006 reauthorization reemphasized this obligation and

<sup>20</sup> See 42 U.S.C. § 1396n(i).

<sup>21</sup> See 42 U.S.C. § 1396n(j).

<sup>22</sup> Older Americans Act of 1965, Pub. L. No. 89-73, § 101.

<sup>23</sup> Older Americans Act Amendments of 1975, Pub. L. No. 94-135, § 106.



directed states to shape an LTSS delivery system that maximizes independence and community-based services.<sup>24</sup>

One of the primary initiatives to arise from the OAA's 2006 reauthorization was the Community Living Program, a program geared toward limiting nursing home placement.<sup>25</sup> The AoA awarded grants to 12 states in 2007, 14 in 2008, and 16 in 2009, with grants ranging from approximately \$300,000 to \$1,000,000.

### **Aging and Disability Resource Centers**

The AoA and CMS combined efforts in 2003 to establish and support Aging and Disability Resource Centers (ADRCs).<sup>26</sup> The ADRCs are designed to be “one-stop shops” for consumer information on long-term services options, with a primary goal being to prevent “default” admissions to nursing homes. With the 2009 awards, more than 200 ADRCs are operating in 54 states and territories, and CMS has announced its interest in expanding ADRCs further.<sup>27</sup> Some ADRCs are run by state units on aging, others are run by centers for independent living, and some are operated jointly between the two.

### **The Patient Protection and Affordable Care Act (PPACA) of 2010**

The Patient Protection and Affordable Care Act (PPACA, Pub. L. No. 111-148) instructed HHS to promulgate regulations to advance

availability and use of HCBS.<sup>28</sup> In addition, the PPACA authorized a Medicaid State Balancing Incentive Payments Program and a new HCBS attendant benefit. The PPACA also imposed the requirement that, beginning in 2014, states provide protections against spousal impoverishment for spouses of HCBS recipients. Additionally, the law amended the MFP program and HCBS State Plan Benefit to make them more accessible to consumers.<sup>29</sup>

### **The State Balancing Incentive Payments Program**

Under the State Balancing Incentive Payments Program, states that are spending less than 50% of their total Medicaid LTSS dollars on HCBS may be selected to receive an enhanced federal funding match for all HCBS their Medicaid programs cover during the “balancing incentive period.” This period will run from October 1, 2011, to September 30, 2015. Each state must establish goals. A state that devoted less than 25% of its Medicaid LTSS spending on HCBS in fiscal year 2009 must aim to reach 25% no later than October 1, 2015. If selected for participation, these states will receive an increase of five percentage points in their federal Medicaid match for the HCBS they cover during the balancing incentive period.

All other participating states, who have initial percentages from 25% to 49%, must aim to reach 50% by October 1, 2015. These states will receive an enhanced federal match of two percentage points.

<sup>24</sup> Older Americans Act Amendments of 2006, Pub. L. No. 109-365, § 202(b).

<sup>25</sup> U.S. Administration on Aging, Nursing Home Diversion Modernization Grants—Program Announcement and Grant Application Instructions 2 (2007).

<sup>26</sup> Dina Elani & Greg Case, *Aging and Disability Resource Centers: One Contact for Easy Access to Long-Term Care Supports*, 30 TASH Connections 1 (Sept.-Oct. 2004).

<sup>27</sup> State Medicaid Dir. Letter # 10-008 (May 20, 2010).

<sup>28</sup> Pub. L. No. 111-148, § 2402(a).

<sup>29</sup> The State Balancing Incentive Payments Program was authorized by section 10202 of the PPACA. The other provisions were contained in sections 2401 through 2406, under the heading, “New Options for State to Provide Long Term Services and Supports.”



Participating states must use the additional funds for new or expanded HCBS services. Additionally, during the balancing incentive period, states may not make their eligibility standards for HCBS services any more restrictive than the standards in effect on December 31, 2010. The federal government is limited to spending \$3 billion for the program.

### **HCBS Attendant Service Option**

The HCBS Attendant Service Option, or “Community-First Choice Option,” adds a new Medicaid service for persons who meet the state’s clinical eligibility standard for LTSS coverage and offers states the financial incentive to adopt the option.<sup>30</sup> The option provides a broad personal care benefit not subject to waiting lists. A recipient is provided coverage for attendant services necessary to help her accomplish activities of daily living (ADLs) and instrumental activities of daily living (IADLs). It also covers assistance in acquiring, maintaining, and enhancing the skills necessary to accomplish ADLs and IADLs. The benefit recipient must have “consumer control” of the services and may receive training on how to select, manage, and hire providers, who may be family members. The benefit must be available statewide, but is limited to Medicaid beneficiaries with incomes below 300% of the federal Supplemental Security Income (SSI) benefit rate, with no medically needy eligibility permitted for enrollees with higher income.

States that adopt this option receive a six percentage point increase in their federal Medicaid match for the services covered in the benefit, with no limit in how much they spend on the benefit. States are not permitted to impose waiting lists for the benefit.

<sup>30</sup> Pub. L. No. 111-148, § 2401, codified at 42 U.S.C. § 1396(k)(3)(B).

### **Expansion of Spousal Impoverishment Protections**

Spousal impoverishment protections have been mandatory for nursing home residents, but a state option for HCBS. These protections allow the community spouse to retain at least half of the couple’s combined available assets, and to receive an allocation from the nursing home resident’s income when necessary to raise the community spouse’s income to a minimum level set by law.

The PPACA mandates spousal impoverishment protections for HCBS enrollees for the five-year period beginning January 1, 2014. This protection will apply to HCBS waivers and also to certain Medicaid state plan benefits.

### **Improvements to Money Follows the Person Program and HCBS State Plan Benefit**

In the PPACA, Congress extended the MFP program for an additional five years, through fiscal year 2016. New five-year grants will be open both to original grantee states and to states that have not received grants previously.

The PPACA also made MFP more accessible. As enacted by the DRA, MFP payments were only available to persons who had been institutionalized for at least 180 days. In the PPACA, Congress cut this minimum institutional stay in half, from 180 to 90 days.

The PPACA also improved access to the HCBS State Plan Benefit, expanding available services and eliminating the states’ authority to limit enrollment. Additionally, Congress permitted states to make their HCBS State Plan Benefit beneficiaries a separate categorical population. This change allows states to offer income-limit eligibility, without the spenddown requirement that otherwise would be required by medically needy eligibility (see below for information on medically needy eligibility). Congress did not eliminate the overall income limit of 150% of the federal poverty level. However, it did create



two exceptions. First, the limit can be raised to 300% of the federal SSI benefit rate by states that participate in the State Balancing Incentive Payments Program. Second, if a state uses an income limit of 300% of the federal SSI benefit rate for HCBS *waiver* benefits, the state can use the same limit for the HCBS State Plan benefit, but only for persons who meet the clinical eligibility standard for the HCBS waiver program.<sup>31</sup>

### Eligibility Expanded through Separate Categorical Population

In 2010, the federal poverty level is \$903, and 150% of the federal poverty level is thus \$1,355. Assume that Ms. Ruiz needs services and has a monthly income of \$1,200. If, in her state, the HCBS State Plan Benefit does not have a separate categorical population, she will be eligible only by spending down her income to the medically needy income level, which may be as low as \$200. (See Appendix 1 for states' Medically Needy Income Levels.) If, on the other hand, her state has made HCBS State Plan Benefit beneficiaries into a separate categorical population, she can be eligible automatically by virtue of her income being less than \$1,355 monthly.

<sup>31</sup> Under Medicaid law, the HCBS State Plan Benefit must have a clinical eligibility standard that is less restrictive than the standard used by the state for nursing home care/HCBS waiver services. For persons who meet the clinical standard for an HCBS waiver, the availability of the HCBS State Plan Benefit can be very important, as some of them may be on a waiting list for the waiver. Prior to the PPACA, however, a person on a waiver waiting list would also be barred from receiving coverage through the HCBS State Plan Benefit if her income was above 150% of the federal poverty level.

### ADA Litigation Following *Olmstead*

Multiple entities can and have filed suit under the ADA to enforce a state's obligation to operate state programs in a way that does not lead to unnecessary institutionalization. The *Olmstead* ruling confirmed that persons with disabilities can sue. The U.S. Justice Department also can bring ADA litigation, and the Department recently has indicated its interest in these issues by making *Olmstead* enforcement a top priority.<sup>32</sup> When considering cases against institutions, the Department will examine first whether the institution's residents could receive services in a community-based setting instead. The heightened priority has resulted in the Department filing two lawsuits, intervening in a case, and filing amicus briefs in cases in eight states.<sup>33</sup>

Of course, as *Olmstead* has opened the door to litigation, it also has opened the door to new questions about the ADA's application and interpretation. In the 11 years since *Olmstead*, many of these questions (but certainly not all) have been answered in ways favorable to the interests of persons with disabilities.

### States Obligated to Prevent Institutionalization

One question about *Olmstead's* application is whether the ADA's integration mandate applies to persons who are not already institutionalized. The answer is yes: federal courts have recognized that persons living in the community but threatened with institutionalization can bring a claim.

<sup>32</sup> Testimony of Assistant Attorney General Thomas E. Perez before the Senate Committee on Health, Education, Labor, and Pensions, June 22, 2010.

<sup>33</sup> *Id.*



The first case to address this issue was brought against the Oklahoma Medicaid program.<sup>34</sup> Oklahoma’s Medicaid rules limited Medicaid HCBS waiver enrollees to five prescription medications per month, but did not limit medications for nursing home residents. The waiver enrollees sued, arguing that the discrepancy in medication coverage would force them to move into nursing homes. A federal trial court ruled that the integration mandate did not apply to persons already living in the community but, on appeal, an appellate court reversed the trial court on this issue. The appellate court ruled that the ADA protected against unnecessary institutionalization for persons seeking to remain in the community, as well as for those persons seeking to move from an institution into the community. The case was returned to the trial court with instructions that the ADA’s integration mandate applied to the plaintiffs. Shortly thereafter, the case was settled after the Oklahoma Medicaid program eliminated the five-medication limit.

Federal courts across the country have followed this reasoning broadly. Within the past 15 months, federal courts in California have followed this reasoning in reversing California’s planned cutbacks to the In-Home Supportive Services (IHSS) and Adult Day Health Care programs.<sup>35</sup>

### States Obligated to Notify Consumers of HCBS Option

*Olmstead* raises another question, of whether a state can defend itself by saying persons with disabilities failed to explicitly request community placement. In a Connecticut case, a federal trial

court ruled that a state has an obligation not only to develop community-based alternatives, but also to make those alternatives known to persons with disabilities.

The case was brought by residents of a state institution for people with mental health disabilities. The state blamed the residents for their failure to request alternative services, but the court ruled that “[t]he ADA’s preference for integrated settings is not consistent with a procedure in which remaining at [the institution] is the default option for residents.”<sup>36</sup> Thus, a state must take affirmative steps so that consumers are aware that HCBS is available. In the Connecticut case, the court concluded that the state had been negligent in evaluating residents for community placement and in arranging for such placements, in part because of the state’s failure to take the initiative.

### Loosening of Waiver’s Financial Eligibility Standards Not Automatically Fundamental Alteration

Not surprisingly, many post-*Olmstead* cases have considered what type of change to state policies is or is not a “fundamental alteration.” In a Washington state lawsuit against its Medicaid program, a federal appeals court ruled that if a state were forced to provide additional HCBS, that would not necessarily cause a fundamental alteration.<sup>37</sup>

Under Washington state’s Medicaid eligibility rules, income standards for HCBS waivers were stricter than the income standards for nursing home services: medically needy eligibility was available for nursing home residents, but not for waiver enrollees. The plaintiffs requested that the waiver income standards be loosened to be consistent with the income standards for nursing

<sup>34</sup> Fisher v. Oklahoma Health Care Auth., 335 F.3d 1175 (10th Cir. 2003).

<sup>35</sup> V.L. v. Wagner, 669 F.Supp.2d 1106, 1119 (N.D. Cal. 2009) (IHSS); Brantley v. Maxwell-Jolly, 656 F.Supp.2d 1161, 1170 (N.D. Cal. 2009) (ADHC); Cota v. Maxwell-Jolly, 688 F. Supp. 2d 980, 994 (N.D. Cal. 2010) (same).

<sup>36</sup> Messier v. Southbury Training School, 562 F. Supp. 2d 294, 337 (D. Conn. 2008).

<sup>37</sup> Townsend v. Quasim, 328 F.3d 511, 519 (9th Cir. 2003).



home services. In response, the state contended that loosening the income standards would require additional provision of community-based services and thus would automatically constitute a fundamental alteration to the state’s policies.

A federal appeals court rejected the state’s arguments, pointing out that in *Olmstead* itself the plaintiffs were demanding that Georgia add access to HCBS. Further, the court noted that both federal and state Medicaid policies have leaned in recent years toward providing more HCBS, making it less likely that an augmentation of community-based services would automatically be deemed a fundamental alteration. The appellate court sent the case back to the federal trial court with instructions that that “fundamental alteration” be interpreted consistent with the appellate court’s ruling.

### **Modification of Waiver’s Clinical Eligibility Standard Not Automatically Fundamental Alteration**

Similarly, a federal court in Illinois ruled that a fundamental alteration could not be established merely by the fact that a Medicaid program was being asked to expand clinical eligibility standards.<sup>38</sup> The Medicaid beneficiary was requesting at-home services equivalent to hospital care, but the relevant Medicaid waiver only covered nursing-home-level care. The case was particularly compelling because the beneficiary had received the necessary services when he was a minor, as the waiver for minors covered a hospital-equivalent level of care.

In its defense, the state claimed that it could not be expected to change its waiver for adults, because such a change would fundamentally alter the state’s Medicaid program. The federal trial court disagreed, noting that the federal government had not rejected a waiver application

<sup>38</sup> *Grooms v. Maram*, 563 F. Supp. 2d 840, 856-58 (N.D. Ill. 2008).

within the preceding 10 years and that neither the acceptance of persons needing hospital-level care nor the addition of additional waiver services would necessarily constitute a fundamental alteration to the state’s Medicaid program.

### **Added Expense Not Necessarily Fundamental Alteration**

States frequently cite cost as justification to limit or eliminate funding for HCBS. Indeed, in *Olmstead* itself the state of Georgia cited cost as a defense, but the Supreme Court and other federal courts have ruled that budgetary limitations alone cannot justify a state’s inaction.<sup>39</sup>

In general, state budgetary limitations are a factor, but not the only factor when evaluating a fundamental alteration defense. The Supreme Court in *Olmstead* specified that relevant factors include, among other things, the resources available to a state, along with the cost of modifying its policies to provide additional home and community-based services.<sup>40</sup> Two recent rulings against California enunciate the relevant law. Relating to California’s In-Home Supportive Services (IHSS) program, a court said a “budget crisis does not excuse ongoing violations of federal law,”<sup>41</sup> and in reference to the state’s Adult Day Health Care services, a court said “a state defendant cannot rely on budgetary constraints alone as the basis for a fundamental alteration defense.”<sup>42</sup>

<sup>39</sup> See, e.g., *Pa. Protection & Advocacy, Inc. v. Pennsylvania Dep’t of Pub. Welf.*, 402 F.3d 374, 380 (3rd Cir. 2005); *Townsend v. Quasim*, 328 F.3d 511, 520 (9th Cir. 2003).

<sup>40</sup> *Olmstead*, 527 U.S. at 597.

<sup>41</sup> *V.L. v. Wagner*, 669 F.Supp.2d 1106, 1122 (N.D. Cal. 2009) (enjoining California from implementing cuts to IHSS program).

<sup>42</sup> *Cota v. Maxwell-Jolly*, 688 F. Supp. 2d 980, 995 (N.D. Cal. 2010) (enjoining California from implementing cuts to Adult Day Health Care program).



### Plaintiffs Can Cite Systemic, Longer-Term Costs of Institutionalization

When considering whether requested HCBS would be so costly as to constitute a “fundamental alteration,” a New York federal court recently ruled that the cost of those services should be viewed in the context of the longer-term costs of institutional care—specifically, the costs imposed by institutions’ “dependency-based” model.<sup>43</sup> By routinely providing services and billing Medicaid for those services, institutions would likely perpetuate residents’ reliance on Medicaid-reimbursed care. By contrast, a supported housing model could wean those persons from certain services, increasing independence and reducing Medicaid expenditures in the long term.

### *Olmstead* Plans Must Be Specific Regarding State’s Goals and Intentions

As discussed earlier, the Supreme Court in *Olmstead* indicated that a state could, as a defense to an ADA claim, demonstrate a “comprehensive, effectively working plan” for integrating persons with disabilities into less restrictive settings, with a “waiting list that moved at a reasonable pace, not controlled by the State’s endeavors to keep its institutions fully populated.”<sup>44</sup> This requirement can force states to develop and expand their provision of LTSS. On the other hand, *Olmstead* plans are sometimes cited by courts as a reason to rule against consumers in suits seeking more integrated state programs, as is discussed subsequently.

Courts have shown considerable variation in how they have evaluated states’ plans. Consistent with the federal government’s *Olmstead* Letters, some courts have required that state *Olmstead* plans provide significant detail about how persons with

disabilities will be able to receive community-based care rather than institutional care. In 2005, the federal Third Circuit Court of Appeals, which has jurisdiction over federal courts in Pennsylvania and some surrounding states, criticized the State of Pennsylvania for submitting “vague assurance of the individual patient’s future deinstitutionalization rather than some measurable goals for community integration for which [the state] may be held accountable.”<sup>45</sup> Accordingly, the court ruled that a plan must have “reasonably specific and measurable targets for community placement.”<sup>46</sup> At a minimum, the plan must specify a time frame for placement in a community-based setting, the approximate number of persons to be placed, eligibility standards for community-based services, and a general description of how relevant agencies will collaborate.<sup>47</sup> Accordingly, as the same court ruled in a different case the same year, a state’s plan is inadequate if it provides for no more than regular individualized assessment of whether institutionalized persons continue to require institutional services.<sup>48</sup> Also, although past performance is relevant in determining the adequacy of a state’s plan, past success cannot be accepted automatically as proof of future success.<sup>49</sup>

In comparison, the Ninth Circuit Court of Appeals, covering California and other western states, has enunciated a standard that seems to give more leeway to states. One Ninth Circuit decision referred to “a comprehensive deinstitutionalization scheme” that was effective given budgetary restraints and the

<sup>43</sup> Disability Advocates, Inc. v. Paterson, 653 F. Supp. 2d 184, 289, 291-92 (E.D. N.Y. 2009).

<sup>44</sup> 527 U.S. at 605-606.

<sup>45</sup> Frederick L. v. Dep’t of Pub. Welfare of Pa., 422 F.3d 151, 156 (3d Cir. 2005).

<sup>46</sup> *Id.* at 158.

<sup>47</sup> *Id.* at 160.

<sup>48</sup> Pa. Protection & Advocacy, Inc. v. Pa. Dep’t of Pub. Welf., 402 F.3d 374, 384 (3rd Cir. 2005).

<sup>49</sup> Frederick L. v. Dep’t of Pub. Welf. of Pa., 364 F.3d 487, 500 (3rd Cir. 2004).



need to provide other services.<sup>50</sup> Another Ninth Circuit court spoke with favor of states that are “genuinely and effectively in the process of deinstitutionalizing disabled persons with an even hand.”<sup>51</sup>

### **General Expansion of Community-Based Programs Not Necessarily Equivalent to Comprehensive Plan**

The fact that a state has attempted to expand some types of community-based services may not immunize it from liability under the ADA’s integration mandate. In the New York case discussed above, the plaintiffs prevailed at trial despite evidence that the state had added various programs providing community-based services, and that enrollment had increased in several such programs.

The court found that the state’s expansion of programs was insufficient evidence of a plan to move persons with mental illness from large adult homes. To be sure, residents of adult homes had

been added as a target population for a move to supportive housing. However, the state’s priority system generally allocated available supported housing to persons who were leaving certified community residences or psychiatric centers, and to persons who were homeless or near-homeless.<sup>52</sup>

The court’s ruling, in contrast to most of the rulings discussed in this section, was issued after a full trial and completely resolved the parties’ contentions. The court concluded that the state had violated the ADA, and the court issued a stringent order. Under the order, the state must develop at least 1,500 supported housing units per year until there is sufficient capacity, and no fewer than 4,500 total units. In addition, the state must award contracts to supported housing providers to “conduct ‘in-reach’ to residents of adult homes to comprehensively educate them about their choices and to explore the types of services and supports each resident would need to be successful in supported housing.”<sup>53</sup>

<sup>50</sup> Sanchez v. Johnson, 416 F.3d 1051, 1067-68 (9th Cir. 2005).

<sup>51</sup> ARC of Wash., Inc. v. Braddock, 427 F.3d 615, 620 (9th Cir. 2005) (internal quotation omitted).

<sup>52</sup> Disability Advocates, Inc. v. Paterson, 653 F. Supp. 2d 184, 273-75 (E.D. N.Y. 2009).

<sup>53</sup> Disability Advocates, Inc. v. Paterson, 2010 WL 786657, at \*6, 2010 U.S. Dist. LEXIS 17949, at \*22 (E.D. N.Y. 2010).



# PROBLEMS:

## Remaining Issues and Limitations

**D**espite significant post-*Olmstead* progress, many older persons still move into institutions unnecessarily to receive needed long-term services and supports (LTSS). In describing the status quo, Congress included the following statement in the Patient Protection and Affordable Care Act of 2010 (PPACA, Pub. L. No. 111-148):

In 1999, under the United States Supreme Court’s decision in *Olmstead v. L.C.*, 527 U.S. 581 (1999), individuals with disabilities have the right to choose to receive their long-term services and supports in the community, rather than in an institutional setting. Despite the . . . *Olmstead* decision, the long-term care provided to our Nation’s elderly and disabled has not improved. In fact, for many, it has gotten far worse. . . . Although every State has chosen to provide certain services under [Medicaid] home and community-based waivers, these services are unevenly available within and across States, and reach a small percentage of eligible individuals.<sup>54</sup>

This sharp assessment means that, at least in the opinion of Congress, and most likely others, the post-*Olmstead* progress has been insufficient.

Many reasons exist for this state of affairs. The most salient are Medicaid’s continued statutory bias toward institutional care and the myriad barriers that extend from that bias. This section discusses that bias, along with other factors that limit the accessibility and quality of home and community-based services (HCBS). This section also examines several reasons why courts may rule in a state’s favor in *Olmstead* litigation.

<sup>54</sup> Pub. L. No. 111-148, § 2406.

### Medicaid’s Bias in Favor of Institutions

While Medicaid is the single greatest source of coverage for HCBS, Medicaid’s statutory framework generally makes coverage for institutional care easier to attain. Given the shortcomings in HCBS coverage, institutional care becomes the path of least resistance for many people.

#### Institutional Coverage Is Mandatory, But Waivers Are Optional, Limited by Enrollment and Expenditure Caps

The most basic manifestation of Medicaid’s “institutional bias” is that, for persons with a high level of need, states must offer institutional coverage, but are not required to offer a comparable package of HCBS. Specifically, if a Medicaid beneficiary has a clinical need for nursing home care, the state must make nursing home care available. In contrast, the state is not obligated to have an HCBS waiver, although they all do.

More importantly, HCBS waivers generally have enrollment caps. While waiting lists are not allowed for Medicaid coverage of nursing home care, they are common for persons seeking Medicaid coverage for waiver-funded HCBS.

Additionally, states are limited in how much they may spend on HCBS waivers—federal law requires that they not spend more on the waiver population than they would if the population were instead institutionalized. In many states, the end result is that a Medicaid beneficiary with substantial functional or cognitive needs is forced to move into a nursing home to receive necessary assistance, as HCBS coverage for the immediate future is foreclosed by a waiting list.



## **Nursing Home Income Eligibility Rules Are Often More Generous Than Rules Governing Waivers**

Medicaid income eligibility rules demonstrate another instance of Medicaid’s bias toward institutional care. Persons with relatively high incomes may be eligible for nursing home care, but not HCBS waivers.

Most states offer special income-limit eligibility for coverage of nursing home care or HCBS. Almost always, states set the special income limit at the maximum allowed by federal law: 300% of the federal Supplemental Security Income (SSI) benefit level, or \$2,022 in 2010.

Given the expense of nursing home care, and to a lesser extent HCBS, an income of \$2,022 monthly will generally be inadequate to pay for necessary LTSS.<sup>55</sup> As a result, many states also offer medically needy eligibility.

If a state does not permit nursing facility residents to qualify as medically needy, however, it must permit an over-income nursing home resident or an over-income HCBS waiver applicant to qualify for care by establishing, and transferring “excess” income to, an income trust. Under federal Medicaid law, transfers to such trusts are exempt from Medicaid transfer penalties,<sup>56</sup> and the effect of the transfer is to make the person eligible under special income-limit eligibility.

The bias toward institutionalization arises because the use of income trusts is preconditioned on the unavailability of medically

needy eligibility for *nursing home* care. If medically needy eligibility is provided for nursing home residents but not for waiver applicants, the waiver applicants cannot utilize income trusts.

Over-income waiver applicants thus are denied eligibility when a state provides medically needy eligibility to its nursing home residents but not its waiver applicants. The state of Washington had a medically needy program with this disparity, although a federal appellate court found that the disparity was potentially discriminatory under the Americans with Disabilities Act (ADA).<sup>57</sup>

Finally, from a logistical point of view, medically needy eligibility is more feasible in a nursing home setting than in the community. For nursing home residents, the Centers for Medicare & Medicaid Services (CMS) allows a Medicaid program to project monthly expenses at the beginning of the month, and thus to grant eligibility on the first of the month based on the reasonable assumption that the resident will spend down to the medically needy income level during the month. To this point, however, CMS has not allowed similar projecting of expenses in community-based settings. As a result, beneficiaries in the community move from eligibility to ineligibility at the start of each new month, making it much more difficult for them to pay to maintain their service providers.

## **Spousal Impoverishment Protections Are Not Necessarily Available For Waiver Enrollees**

Historically, as discussed above, HCBS enrollees have had a relative disadvantage under Medicaid’s spousal impoverishment rules. These protections have been mandatory for nursing home residents, but have been offered to HCBS enrollees at a state’s option. The PPACA has made the protections mandatory for spouses of HCBS

<sup>55</sup> In 2010, the national median annual rate for nursing home care is \$75,190, or \$6,265 a month, and the national median hourly private pay rate for a home health aide is \$19. Genworth Financial, Genworth 2010 Cost of Care Survey 5 (Apr. 2010). A monthly income of \$2,022 thus is only one-third of the median nursing home rate. The same income may also be inadequate to pay for home health care, as home health aide assistance for four hours a day would exhaust the income in a 30-day month.

<sup>56</sup> 42 U.S.C. § 1396p(d)(4)(B).

<sup>57</sup> Townsend v. Quasim, 328 F.3d 511 (9th Cir. 2003).



enrollees, but this provision is not effective until January 1, 2014, and then only through the end of 2018.

### Access to Home Health Services and Personal Care Services Is Relatively Limited

The Medicaid home health services benefit was added as a mandatory service in 1967, two years after Medicaid was enacted, to address the program’s already-recognized bias toward institutionalization.<sup>58</sup> Home health, however, is a single service, and the benefit generally is not robust enough for a person who may otherwise be facing institutional care, especially when the state imposes strict limits on coverage. The same often holds true for Medicaid’s personal care benefit: the benefit package and clinical eligibility standards may be unduly narrow. In addition, the benefit is optional for states under federal law and as many as 15 states do not offer the benefit.<sup>59</sup>

Even when a state’s coverage for home health services or personal care services is relatively generous, Medicaid’s financial eligibility rules make nursing home care easier to attain. A person with income between \$904 and \$2,022 is likely to qualify automatically for nursing home care, but not for home health services or personal care services.

Here is why. States generally must provide Medicaid coverage to recipients of SSI. These are persons who are at least 65 years old and/or have a disability, and in general have less than \$2,000 in savings and less than \$674 (in 2010) in monthly income. For other older persons and persons with disabilities, states have the

option to provide automatic Medicaid eligibility to those with incomes at or below 100% of the federal poverty level (FPL), which is \$903 monthly in 2010.

If Mr. Jones has income of \$950, he generally will not be able to receive the services unless the state offers “medically needy” eligibility. “Medically needy” persons meet Medicaid’s categorical eligibility requirements (e.g., 65 years old or with a disability) and have income over their state’s special income limit, but do not have sufficient income to pay for their health care. The problem is that medically needy eligibility requires payment of a monthly deductible (the “spenddown”) that usually is far more than someone like Mr. Jones can practically afford. The deductible is the difference between the person’s income and the state’s medically needy income level (MNIL).

In the vast majority of states, the MNIL is lower than the SSI rate—which causes the unreasonably high deductible.<sup>60</sup> For example, in 2009, the MNILs for Arkansas, Maryland, and Wisconsin were \$108, \$350, and \$592, respectively. (See Appendix #1 for MNIL of each state offering medically needy eligibility.) In most states, the MNIL’s low amount is attributable to a federal law that tethers the MNIL’s amount to 1996 public benefits levels, adjusted for inflation.<sup>61</sup>

If, however, Mr. Jones enters a nursing home, the income eligibility rules become significantly more favorable. Federal law permits states to offer special income-limit eligibility for nursing home services. This income limit can be up to 300% of the SSI federal benefit rate, or \$2,022 a month for 2010 ( $674 \times 3 = 2,022$ ). In a state

<sup>58</sup> See Social Security Amendments of 1967: Hearings before the Committee on Finance, United States Senate, on H.R. 12080, 90th Cong. 894 (1967).

<sup>59</sup> Cliff Binder, Congressional Research Service, Medicaid’s Home and Community-Based Services State Plan Option: Section 6086 of the Deficit Reduction Act 2 (updated January 31, 2008), available at <http://aging.senate.gov/crs/medicaid17.pdf>.

<sup>60</sup> See Kaiser Family Foundation: Income Eligibility Requirements including Income Limits and Asset Limits for the Medically Needy in Medicaid, 2009, available at <http://www.statehealthfacts.org/comparereport.jsp?rep=60&cat=4>.

<sup>61</sup> 42 U.S.C. §§ 1396b(f)(1)(B)(i), 1396u-1(f)(3).



that adopts this option, someone with a \$1,500 monthly income can enter a nursing home and automatically qualify for Medicaid, but the same person will be eligible for home health services or personal care services only if, as described above, the state offers coverage to the medically needy, and the person spends down to the MNIL.

In addition, Medicaid eligibility remains possible for nursing home residents with income exceeding \$2,022. If the state offers coverage to the medically needy, Mr. Jones will easily meet the spenddown requirement in a nursing home, as the facility’s monthly charge will likely consume all of his income. He will not be faced with the same quandary relating to the MNIL amount being too low to cover food and shelter costs, as a nursing home resident receives these as part of the facility’s Medicaid-covered services.

### Why Mr. Jones Can’t Afford Both Home Health Care and Basic Necessities

Mr. Jones has a monthly income of \$1,000. He lives in Kansas, which currently has a medically needy income level (MNIL) of \$475.<sup>62</sup> He will have to incur monthly medical expenses of \$525 before attaining eligibility. Although he then may have access to home health services or personal care services, he will have little remaining income to pay for room, board, and other basic needs.

<sup>62</sup> Kansas Health Policy Authority, Kansas Medical Assistance: Overview of Programs for Elderly and Persons with Disabilities (August 2010), available at [www.khpa.ks.gov/healthwave/eligibility\\_guidelines.html](http://www.khpa.ks.gov/healthwave/eligibility_guidelines.html).

### HCBS Coverage Does Not Include Room and Board, and Medicaid Income Allocations Are Inadequate

Under federal law, a Medicaid program generally cannot include room and board<sup>63</sup> and a Medicaid enrollee is expected to pay for room and board from his income. The limited exceptions to this rule include care in hospitals and nursing homes, where room and board is interwoven with health care services.

The enrollee’s income, however, often is inadequate, and the inability to pay for room and board is a frequent sticking point in efforts to rebalance LTSS systems toward HCBS.

For example, to qualify for HCBS waivers, common eligibility standards are monthly income at or below 300 percent of the federal SSI benefit rate, and \$2,000 in resources. But eligibility is not the end of the story for a Medicaid HCBS waiver enrollee. A post-eligibility calculation is applied to determine how much income an enrollee is able to retain for his community needs—his “personal needs allowance,” or PNA.

The PNA is the portion of the enrollee’s income that he or she is permitted to keep to pay for ongoing expenses of room and board, as well as other expenses not covered by Medicaid. States vary in their PNAs, but many states only permit an allowance equal to the SSI benefit rate or a somewhat higher amount. In many cases, the PNA is insufficient.

<sup>63</sup> 42 U.S.C. §1396n(c)(1).



### Why Mr. Frank Qualifies For Waiver Services But Can't Afford Other Expenses

Assume a state has set its financial eligibility standard for an HCBS waiver at \$2,022 a month for income and \$2,000 in resources, and permits a \$700 personal needs allowance (PNA). Mr. Frank has \$1,500 in available monthly income and \$1,900 in resources. He will qualify once enrolled and receiving services, but he will have to contribute \$800 each month toward the Medicaid-covered services he receives as a waiver enrollee (1,500 – 700 = 800). His \$700 PNA must suffice for room and board, transportation, clothing, and all other non-health-care related expenses.

### Optional Nature Makes Community Services Budget-Cut Targets

Federal law requires that state Medicaid programs offer coverage for home health services.<sup>64</sup> Otherwise, virtually all other at-home Medicaid services are optional for states, whether the services are provided through HCBS waivers or not. Coverage for personal care services, for example, is an option for states. The same is true of the adult day health services in many states. The optional nature of these services means that they are often targeted for reduction or elimination when states encounter economic difficulties. Nursing home coverage, by contrast, is generally invulnerable. During the recent economic downturn, at least 25 states have made

cuts to Medicaid HCBS for older persons or persons with disabilities.<sup>65</sup>

### Limited Quality of Care Standards in HCBS Waivers

The HCBS waiver law requires that states assure CMS that “necessary safeguards (including adequate standards for provider participation) have been taken to protect the health and welfare of individuals provided services under the waiver.”<sup>66</sup> Beyond this language, however, there is relatively little in federal Medicaid law to ensure the quality of services provided in HCBS waivers; as a result, the federal government has had little control over the quality of services provided by Medicaid HCBS programs. In one recent exception, CMS has expressed its interest in developing participant experience measures to improve the quality of life for persons receiving HCBS.<sup>67</sup>

A 2003 General Accounting Office (GAO)<sup>68</sup> report noted a significant increase in federal spending on HCBS waiver programs, but without an appreciable federal presence in ensuring quality of care. The report said that states’ waiver applications and reports “often contained little or no information on state mechanisms for assuring quality in waivers,” giving CMS little ability to monitor the quality of care provided.<sup>69</sup> CMS regional offices have responsibility for monitoring quality in the states

<sup>64</sup> 42 U.S.C. § 1396a(a)(10)(D).

<sup>65</sup> John Leland, Cuts in Home Care Put Elderly and Disabled at Risk, N.Y. Times, July 16, 2010, available at [http://www.nytimes.com/2010/07/21/us/21aging.html?\\_r=2&hp](http://www.nytimes.com/2010/07/21/us/21aging.html?_r=2&hp).

<sup>66</sup> 42 U.S.C. § 1396n(c)(2).

<sup>67</sup> Letter from the Center for Medicaid and State Operations to State Medicaid Directors 6 (May 20, 2010), available at <https://www.cms.gov/smdl/downloads/SMD10008.pdf>.

<sup>68</sup> The agency’s name was changed to the Government Accountability Office in 2004.

<sup>69</sup> GAO, Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened, GAO-03-576, at 1 (June 2003).



within a region, but this obligation in practice is given little attention. The GAO concluded that waiver programs overall had significant quality of care problems, as the federal government had no credible mechanism to ensure quality.<sup>70</sup>

Limited federal interest in HCBS quality of care is in dramatic contrast to the federal government’s interest in nursing home quality of care. The federal Nursing Home Reform Law has applied since 1990 to every nursing home certified to accept reimbursement from Medicaid or Medicare. The Reform Law has set detailed standards for virtually every aspect of nursing home care, including assessment, care planning, staffing, and resident rights, and is enforced through a comprehensive state survey system.<sup>71</sup>

### Limited Assurance That Services Provided in Assisted Living Facilities are Community-Based

Federal regulations imply that assisted living facilities can be deemed “community” residences,<sup>72</sup> but there has been little assurance that a participating facility truly provides “community-based” services. The standard Medicaid HCBS waiver application template merely asks states to “describe how a home and community character is maintained” in facilities with four or more residents, and a standard response is for a state to list various state assisted living regulations pertaining to resident rights and quality of care.<sup>73</sup>

In authorizing the Money Follows the Person (MFP) program, Congress added a wrinkle to this issue by limiting the enhanced federal

reimbursement to services provided to Medicaid enrollees transitioning to a “qualified residence.”<sup>74</sup> This is defined as a private home, a residence in which no more than four unrelated persons reside, or an apartment with an “individual lease, with lockable access and egress, and which includes living, sleeping, bathing, and cooking areas over which the individual or the individual’s family has domain and control.” Most assisted living facilities do not meet these requirements and thus are not eligible for MFP-funded transitions from nursing homes.

The MFP limitation is a signal that assisted living facilities may come under greater scrutiny, and other recent CMS actions further reflect this. CMS has issued notice of its intent to develop “standards for community living facilities” in which enrollees receive services. CMS will apply additional scrutiny if an enrollee is “living in a residence with four or more persons unrelated to the proprietor, which furnishes one or more treatments or services.”<sup>75</sup> Under this scrutiny, CMS will consider the degree to which the resident: controls access to, and furnishes, private living quarters; has privacy for visits and telephone calls; and has access to food and a kitchen at unscheduled times.

### Limitations Within ADA and *Olmstead*

States in general have defended *Olmstead* litigation vigorously. Discussed below are some of the more important issues that have been resolved in favor of state defendants. This list of issues is not all-inclusive.

<sup>70</sup> GAO, Long-Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened, GAO-03-576, at 1 (June 2003).

<sup>71</sup> 42 U.S.C. §§ 1395i-3, 1396r.

<sup>72</sup> 42 C.F.R. §§ 441.302(a)(3), 441.310(a)(1).

<sup>73</sup> See, e.g., New Jersey Global Options for Long-Term Care, Waiver Application, Appendix C-2(c)(ii).

<sup>74</sup> Pub. L. No 109-171, § 6071(b)(6); 42 U.S.C. § 1396a note.

<sup>75</sup> 73 Fed. Reg. 18,676, 18,697 (2008) (proposed 42 C.F.R. § 441.556(3)).



### **Olmstead Plan Used by State as Legal Defense**

Although “*Olmstead*” has become shorthand for the movement away from institutional care, a state’s obligation is qualified: the state is only required to make “reasonable modifications” and is excused from making changes that could constitute a “fundamental alteration.”<sup>76</sup> Also, a state is given credit for good faith efforts to develop non-institutional alternatives. As noted elsewhere in this report, a state generally is deemed to be in compliance if it has a comprehensive plan, and a waiting list, if any, moves at a reasonable pace.<sup>77</sup>

Thus, a state’s development of an *Olmstead* plan has become a double-edged sword for persons seeking expansion of non-institutional alternatives. On one hand, implementation of a good-faith plan obviously makes it more likely that persons with disabilities will be able to live in the community. On the other hand, a state can and has used a plan as a defense in ADA litigation. As a result, some commentators and disability advocates have criticized existing state plans, and courts’ deference to them, as roadblocks to integration.<sup>78</sup>

For example, the State of California cited its *Olmstead* plan when sued for paying community-based service providers lower wages and benefits than it paid to employees in state institutions. Allegedly, this disparity in

pay led to unnecessary institutionalization of developmentally disabled persons. The ADA claim was rejected by a federal trial court and then by a federal appellate court, each of which noted that the state’s *Olmstead* plan seemed credible, and that the state had shown success in moving persons with developmental disabilities out of institutions. The appellate court noted that the state’s plan reflected a balancing of various considerations, including “existing budgetary constraints and the competing demands of other services that the State provides.”<sup>79</sup>

A federal trial court came to a similar conclusion in ruling for Maryland in a suit alleging that the state had failed to provide non-institutional alternatives for persons with mental health disabilities.<sup>80</sup> In the previous 10 years, the state had closed institutions and developed small group homes and community-based programs. Over a longer period of time, the population of the state’s mental hospitals had dropped from approximately 7,100 to 1,200. The state had developed Medicaid HCBS waivers, and had given careful consideration to other Medicaid options, such as demonstration waivers and case management programs.

### **Cost Comparisons Cannot Necessarily Assume Elimination of All Institutional Costs**

In *Olmstead* itself, the Supreme Court ruled that cost comparisons cannot be reduced solely to the cost of HCBS versus the cost of institutional care. A state will not be able to entirely eliminate its institutions, and a reduction in the number of institutionalized persons will not eliminate certain fixed costs of operating institutions. This same point has been made by other courts in

<sup>76</sup> 28 C.F.R. § 35.130(b)(7).

<sup>77</sup> *Olmstead*, 527 U.S. at 605-606.

<sup>78</sup> See, e.g., Charles R. Bliss & C. Talley Wells, *Applying Lessons from the Evolution of Brown v. Board of Education to Olmstead: Moving from Gradualism to Immediate, Effective, and Comprehensive Integration*, 26 Georgia State L. Rev. 705 (Spring 2010); Julia Gilmore Gaughan, Institutionalization as Discrimination: How Medicaid Waivers, the ADA and § 1983 Fail, 56 U. Kan. L. Rev. 405 (Jan. 2008); Samantha A. DiPolito, *Olmstead v. L.C.: Deinstitutionalization and Community Integration: An Awakening of the Nation’s Conscience?*, 58 Mercer L. Rev. 1381 (Summer 2007).

<sup>79</sup> *Sanchez v. Johnson*, 416 F.3d 1051, 1067 (9th Cir. 2005).

<sup>80</sup> *Williams v. Wasserman*, 164 F. Supp. 2d 591, 634-35 (D. Md. 2001).



subsequent years.<sup>81</sup> The result is that a plaintiff under the ADA must be prepared to counter the argument that the increased use of less expensive HCBS will lead to higher overall costs, at least during a transition period in the state’s public policy.

**ADA May Not Require Provision of “New” Services**

In states within the federal Second Circuit (namely, New York, Connecticut, and Vermont), the federal courts interpret the ADA in a particularly narrow fashion, focusing on whether the plaintiff is requesting services that would be available to him in an institutional setting. The seminal case from the Second Circuit Court of Appeals states:

*Olmstead* does not, therefore, stand for the proposition that states must provide disabled individuals with the opportunity to remain out of institutions. Instead, it holds only that “States must adhere to the ADA’s nondiscrimination requirement with regard to the services they in fact provide.”<sup>82</sup>

Based on this reasoning, the court ruled that the New York Medicaid program was not obligated to include safety-monitoring services along with other personal care services. Another court in the same circuit similarly ruled that the Connecticut Medicaid program was not obligated to initiate a program to pay for assisted living facility services.<sup>83</sup> In the court’s view, the Connecticut Medicaid program did not cover assisted living services for anyone and, as a result, the plaintiff could not show any discrimination.

<sup>81</sup> See, e.g., *Williams v. Wasserman*, 164 F. Supp. 2d 591, 636-37 (D. Md. 2001).

<sup>82</sup> *Rodriguez by Rodriguez v. City of New York*, 197 F.3d 611, 619 (2nd Cir. 1999).

<sup>83</sup> *Leocata v. Wilson-Coker*, 343 F. Supp. 2d 144 (D. Conn. 2004).



# RECOMMENDATIONS: Call to Action

Included in the Patient Protection and Affordable Care Act of 2010 (PPACA, Pub. L. No. 111-148) was a “Sense of the Senate” declaration that “during the [next] session of Congress, Congress should address long-term care services and supports in a comprehensive way that guarantees elderly and disabled individuals the care they need, and . . . long-term services and supports should be made available in the community in addition to institutions.”<sup>84</sup>

This declaration reinforces the widely held view that expansion of home and community-based services (HCBS) is needed to better maintain the independence and dignity of persons needing long-term services and supports (LTSS). Based on progress made to date and the remaining problems and limitations that hamper progress, there are specific steps that the federal and state governments should take to meet this goal.

## End Medicaid’s Institutional Bias

### 1. Make Medicaid Coverage for HCBS an Entitlement

As long as entering an institution such as a nursing home is the surest way to access Medicaid-funded LTSS, the system’s current bias will continue. Incremental additions by Congress over the years have increased access to HCBS, but the sum total of these additions has been insufficient, by Congress’ own admission. In order to achieve significant change, Medicaid must provide a guarantee of support beyond home health care or personal care services.

### 2. Harmonize Eligibility Standards for Coverage of Nursing Home Care and HCBS

Institutional coverage under Medicaid is not more widely available simply because coverage is mandatory, but also because the financial eligibility standards are more accommodating. To balance Medicaid’s LTSS system, financial eligibility procedures should be the same whether the enrollee is receiving institutional care or HCBS.

For example, either Congress or the Centers for Medicare & Medicaid Services (CMS) should require states that provide medically needy eligibility for institutionalized persons to provide medically needy eligibility for waiver services. This practice would be consistent with the federal appellate ruling discussed previously.

Additionally, the HCBS State Plan Benefit and community attendant services benefit should have their program-specific income caps removed so that all persons who qualify under the state’s general Medicaid LTSS rules may access the benefits. Congress should permit states to make a separate categorical population for those who receive the community attendant services benefit. This change would allow persons with higher incomes to automatically qualify, just as they already do for institutional services and HCBS waiver services, and will soon do for the HCBS State Plan Benefit. Finally, CMS should allow Medicaid programs to project expenses for waiver recipients at the beginning of the month, just as programs may now project expenses for nursing home residents.

<sup>84</sup> Pub. L. No. 111-148, § 2406.



### 3. Now and Permanently Mandate Medicaid Spousal Impoverishment Protections for Spouses of HCBS Enrollees

Under current federal law, spousal impoverishment protections are mandatory for spouses of institutionalized enrollees, but not for spouses of HCBS enrollees. The PPACA repairs this discrepancy, but not until 2014, and the legislation is scheduled to sunset in 2019. The need for equivalent protections exists now, so the extension of the protections should not be delayed until 2014, and the extension should not sunset in 2019.

### 4. Establish Income Allocations Sufficient to Allow Medicaid Enrollees to Afford Room and Board Expenses

Medicaid coverage of community-based services is ultimately impractical if the enrollee does not retain enough income to meet, at a minimum, his room and board expenses. Medicaid programs should set the Personal Needs Allowance (for special income-limit eligibility) at levels that are sufficient to cover room and board expenses. Likewise, for medically needy eligibility, Medicaid programs should offer targeted income deductions that enable a Medicaid beneficiary to afford room and board even after spending down available income to the medically needy income level. Alternatively, Congress should repeal or amend the federal law that ties a state's medically needy income level to the state's 1996 public benefits level.

## Improve Quality of Care

### 5. Ensure Adequate Quality of Care in HCBS Settings

CMS has an obligation to assure the quality of HCBS, but too frequently CMS has deferred to states' written assurances of compliance. Particularly given that HCBS waiver enrollees are persons whose health care needs would qualify them for nursing home care, CMS should take

steps to set quality standards for Medicaid-funded HCBS, and then to meaningfully enforce those standards. Providers and other stakeholders also bear responsibility for maintaining appropriate care standards.

### 6. Ensure Community-Based Character of Settings Where HCBS Are Provided

HCBS waiver payment has been made routinely for services provided in assisted living facilities, with little focus on whether the setting is truly non-institutional. CMS should establish requirements comparable to the "qualified residence" requirements in the Money Follows the Person (MFP) program, to assure that an assisted living facility or any other residential care facility is truly providing a home or community-based setting. These requirements should apply consistently to any and all Medicaid HCBS funding.

## Enhance State Commitment

### 7. Participate in Expanded HCBS Options

States should adopt the full range of HCBS options available under Medicaid, which ultimately provides states with a financial benefit. Research has shown that states can save money by transitioning persons from institutions to the community.<sup>85</sup> States are already reimbursed by the federal government for at least 50% of their Medicaid costs (28 states and Washington, D.C., are reimbursed 60% or more<sup>86</sup>). The states also are being offered a rate increase for participating in the State Balancing Incentive Payments Program and adopting the HCBS attendant service option.

<sup>85</sup> H. Stephen Kaye, Mitchell P. LaPlante, & Charlene Harrington, *Do Noninstitutional Long-Term Care Services Reduce Medicaid Spending?*, Health Affairs, Jan./Feb. 2009, at 262.

<sup>86</sup> Federal Financial Participation in State Assistance Expenditures, 73 Fed. Reg. 72,051- 72,053 (November 26, 2008).



Additionally, the PPACA’s extension of the MFP program, which also contains a financial incentive, allows new states to participate.

**8. Establish Compliance Standards for States Receiving Federal Money Based on Promises to Advance Community-Based Care**

The MFP program and the State Balancing Incentive Payments Program each provide participating states an increase in the federal financial reimbursement rate for the coverage of community-based services. There are, however, no consequences for states that fail to attain projected goals. To encourage compliance, financial assistance should be accompanied by enforceable expectations that the state will deliver the promised results.

**Improve Coordination of Programs and Services**

**9. Emphasize HCBS in 2011 Reauthorization of Older Americans Act**

When the Older Americans Act (OAA) was reauthorized in 2006, Congress heightened the priority associated with HCBS expansion. In the upcoming 2011 reauthorization, Congress should both reinforce this priority and assess progress made toward this goal since 2006.

**10. Develop Consistent Funding Sources for Aging and Disability Resource Centers**

Arranging and maintaining LTSS at home is not an easy task, and consumers generally cannot be expected to take it on without guidance. Aging and Disability Resource Centers (ADRCs) are envisioned as an antidote to the delivery system’s fragmentation, but AoA funding for ADRCs has been limited in scope and in time. To truly support consumer decision-making, funding should be adequate to support further ADRC development and maintenance into the foreseeable future. Congress demonstrated support for

ADRCs by authorizing \$10 million a year through 2014, in addition to other funds in the OAA used for ADRCs. However, the importance of the program justifies a funding commitment more focused and of longer duration.

**11. Coordinate Federal Programs from the Centers for Medicare & Medicaid Services (CMS), the Department of Housing and Urban Development (HUD), and the Administration on Aging (AoA).**

For HCBS programs to work properly, services and housing must be adequate and affordable, and the system must be organized in such a way that a consumer can understand her options and make the necessary decisions. These three components—services, housing, and decision-making—are addressed in programs operated by CMS, HUD, and AoA, respectively. These three agencies should increase their cooperation so as to increase HCBS’s real-world accessibility.

In a positive development, the Department of Health and Human Services and HUD partnered earlier this year to make \$40 million available over 12 months for 5,300 “Housing Choice Vouchers” specifically for non-elderly persons with disabilities. Additionally, 10 MFP-participating states set aside state funding for rental assistance to be used when MFP participants await qualification for HUD subsidies. Additional initiatives from both the federal and state governments should be introduced.

**Conclusion**

The 11 years since the *Olmstead* ruling have brought much progress, but challenges remain. To realize an LTSS system that is less reliant on institutionalization, the federal and state governments should implement the above recommendations. Increased use of HCBS would bring more dignity and independence to the lives of persons requiring LTSS, and it has great potential to reduce federal and state costs over the long term.



## Appendix 1: Medically Needy Income Limits

	Medically Needy Program?	Monthly Income Limit
Alabama	No	—
Alaska	No	—
Arizona	Yes	\$360
Arkansas	Yes	\$108
California	Yes	\$600
Colorado	No	—
Connecticut	Yes	\$476/\$576 <sup>87</sup>
Delaware	No	—
District of Columbia	Yes	\$577
Florida	Yes	\$180
Georgia	Yes	\$317
Hawaii	Yes	\$469
Idaho	No	—
Illinois	Yes	\$483
Indiana	Yes	\$903
Iowa	No	—
Kansas	Yes	\$495
Kentucky	Yes	\$217
Louisiana	Yes	\$100/\$922 <sup>88</sup>
Maine	Yes	\$903
Maryland	Yes	\$350
Massachusetts	Yes	\$903/\$1,200 <sup>89</sup>
Michigan	Yes	\$341-\$408 <sup>90</sup>
Minnesota	Yes	\$677
Mississippi	No	—
Missouri	No	—

<sup>87</sup> Region A \$576; Regions B and C \$476

<sup>88</sup> Urban counties \$100; Rural counties \$922

<sup>89</sup> \$1,200 for those with Professional Care Assistance

<sup>90</sup> Region 1 \$341; Region 2 \$341; Region 3 \$350; Region 4 \$375; Region 5 \$391; Region 6 \$408

	Medically Needy Program?	Monthly Income Limit
Montana	Yes	\$625
Nebraska	Yes	\$392
Nevada	No	—
New Hampshire	Yes	\$591
New Jersey	Yes	\$367
New Mexico	No	—
New York	Yes	\$767
North Carolina	Yes	\$242
North Dakota	Yes	\$750
Ohio	No	—
Oklahoma	No	—
Oregon	No	—
Pennsylvania	Yes	\$425
Rhode Island	Yes	\$800
South Carolina	No	—
South Dakota	No	—
Tennessee	Yes	\$241
Texas	No	—
Utah	Yes	\$370
Vermont	Yes	\$916/\$991 <sup>91</sup>
Virginia	Yes	\$281-421 <sup>92</sup>
Washington	Yes	\$674
West Virginia	Yes	\$200
Wisconsin	Yes	\$592
Wyoming	No	—

<sup>91</sup> \$991 for Chittenden County

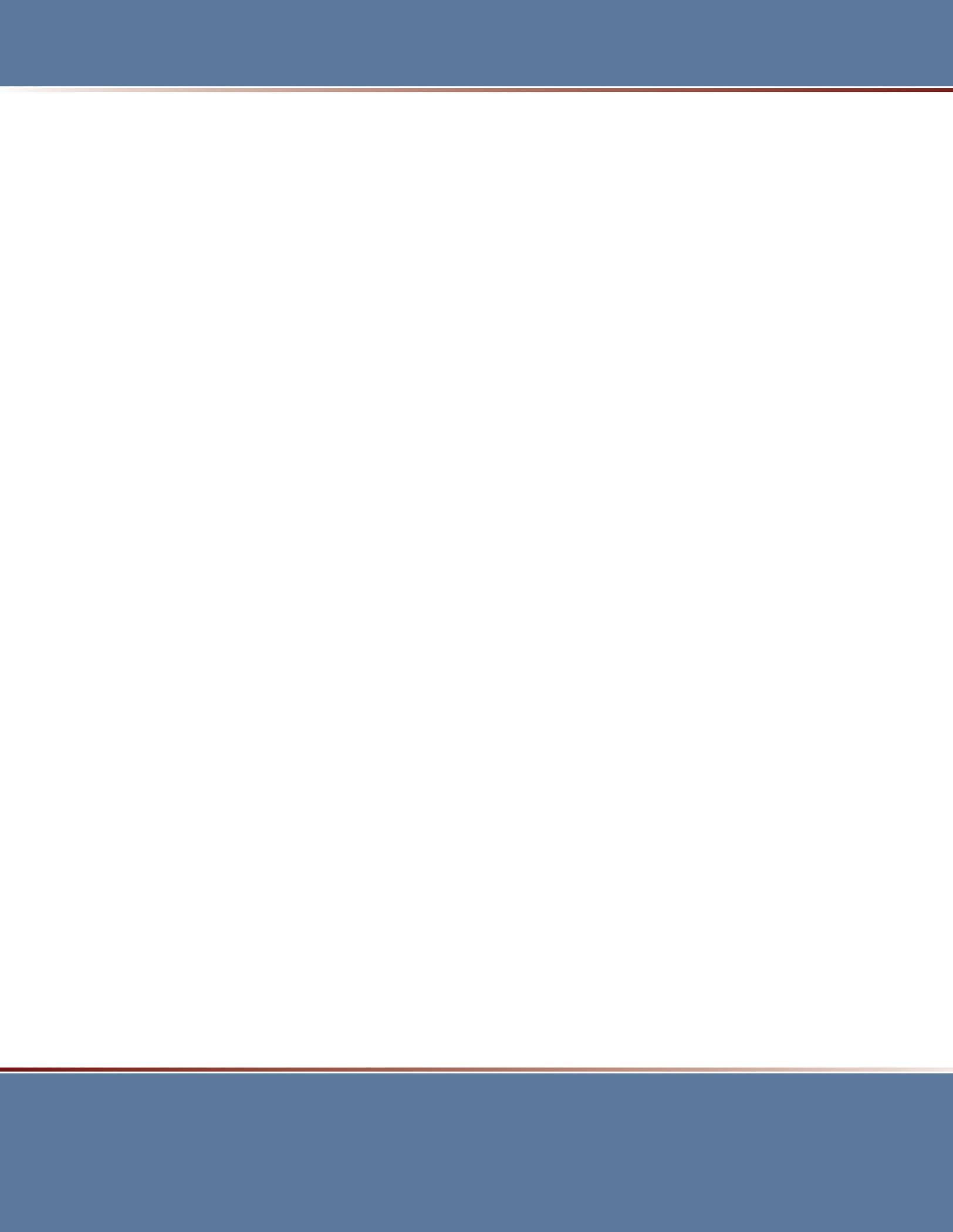
<sup>92</sup> Group I \$281; Group II \$324; Group III \$421

*Information from Income Eligibility Requirements including Income Limits and Asset Limits for the Medically Needy in Medicaid, 2009, by statehealthfacts.org, a project of The Henry J. Kaiser Family Foundation.*



# NOTES





The National Senior Citizens Law Center is the only national non-profit whose principal mission is to protect the rights of low income older adults. Through advocacy, litigation, and the education and counseling of local advocates, we make the law work to ensure their health, economic security and access to the courts.

