United States Senate

HEALTH, EDUCATION, LABOR, AND PENSIONS COMMITTEE

Tom Harkin, Chairman

Separate and Unequal: States Fail to Fulfill the Community Living Promise of the Americans with Disabilities Act

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Executive Summary

- The Supreme Court's 1999 decision in *Olmstead v. L.C.* put states on notice that unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act (ADA) of 1990. The ruling was hailed as the disability civil rights equivalent to *Brown v. Board of Education*, which ordered the desegregation of the nation's public schools.

- The *Olmstead* decision clearly articulates that ensuring individuals with disabilities are able to exercise their right to participate as citizens of the state and the country is a protected civil right under the ADA. *Olmstead* envisioned that states will provide appropriate long-term services and supports (LTSS) to individuals with disabilities through home and community-based services (HCBS) and end forced segregation in institutions.

- Previous testimony before the Committee illustrates the discriminatory nature of institutionalization. One individual stated simply: "People need to have high expectations for people with disabilities because then they'll give them opportunities to learn and grow. People don't grow in…institutions."

- Nationally, there has been a fundamental rebalancing of spending on individuals with disabilities in institutions as compared to spending on HCBS in the years since the *Olmstead* decision. Between 1995 and 2010, states reduced the share of Medicaid spending on institutions, including nursing homes, mental hospitals, and institutions for people with intellectual and developmental disabilities, from 79 percent to 50 percent.

- However, these numbers fail to paint a complete picture. In reality, only 12 states spent more than 50 percent of Medicaid LTSS dollars on HCBS by 2010. Further, the population of individuals with disabilities under 65 in nursing homes actually increased between 2008 and 2012. This is true even though 38 studies over the past seven years have clearly demonstrated that providing HCBS is more cost-effective than providing services in an institution.

- Last year, on the 13th anniversary of the *Olmstead* decision, Chairman Harkin requested information from all 50 states on the progress being made to ensure that all individuals with disabilities have the opportunity to live independently in the community through the use of HCBS.

- The result of the survey demonstrates that, with a few exceptions, state leaders continue to approach decisions regarding Medicaid from a social welfare and budgetary perspective. For the promise of *Olmstead* to be fully realized, state leaders must also approach decisions about Medicaid delivery options from a civil rights perspective. To do so, states must create an *Olmstead* plan with enforceable benchmark targets—one that fully evaluates whether a state can take advantage of new federal options to better ensure that individuals can live in community-based settings where they can fully participate and be granted the power of individual decision making and choice.

Findings

- Providing services for people with disabilities outside of an institutional setting is more cost-effective than providing care in an institution.

    - Thirty-eight studies published from 2005 to 2012 found that providing HCBS is less costly than providing institutional care.

- Fourteen of the responding states provided data showing that the average cost for individuals in nursing or intermediate care facilities (ICFs) is greater than the cost per person of providing HCBS.
    - Arizona reported that, since 1998, its "HCBS placement percentage has increased by over 30 percent, which has resulted in $300 million in savings."
    - Washington reported being able to serve seven individuals in one of its HCBS programs for the same cost as serving a single individual in an ICF.
    - The average cost per individual served by Alabama's Independent Living program was $10,718. In contrast, the average cost per individual served in an Alabama nursing facility (NF) was $36,593—a $25,000 difference.

- Consistent with the national trend toward increased spending on Medicaid HCBS over the past 15 years, most states that responded to the Chairman's letter increased the portion of Medicaid spending devoted to HCBS from 2008 to 2012.
    - Of 11 states selected for follow-up discussions, the highest proportion of spending on HCBS was 81 percent; the lowest proportion spent on HCBS programs was 37 percent.

- While most of the responding states also increased the number of individuals served in community settings from 2008 to 2012, they also reported transitioning more individuals with disabilities from institutions into other congregate settings, including group homes, assisted living facilities, and other shared living arrangements.

- The increase in spending and individuals served by HCBS is occurring against a backdrop of state budget cuts, rising health care delivery costs, and an increase in the size of the Medicaid-eligible population.

- However, widespread inequities in access to HCBS still exist across states.
    - In 2009, the percentage of spending on HCBS LTSS varied from more than 80 percent to less than 20 percent, and 38 states spent less than 50 percent of LTSS costs on HCBS.
    - Hundreds of thousands of people with disabilities remain on waiting lists for HCBS services.

- Progress in providing HCBS for persons with physical disabilities and mental illnesses has lagged significantly behind efforts for individuals with intellectual and developmental disabilities.
    - Of 11 states selected for follow-up discussions, ten provided at least one HCBS program for individuals with intellectual or developmental disabilities, but only four provided HCBS programs for individuals with physical disabilities.
    - Reports also show that people with mental illnesses remain segregated in NFs and other institutional placements. Only four of 11 follow-up states provided a HCBS program for individuals with mental illnesses.

- People younger than 65 are increasingly being isolated in nursing homes.

- Studies show that from 2000 to 2007, nursing home use increased among adults age 31 to 65 in 48 states. Nationwide, the proportion of nursing home residents younger than 65 increased from 12.9 percent in 2005 to 14.2 percent in 2009.

- Current data shows that there are still more than 200,000 individuals younger than 65 in nursing homes—almost 16 percent of the total nursing home population.

➢ Perceived uncertainty about the potential total cost of providing HCBS to every eligible individual in the state may be preventing states from exercising new federal options for HCBS.

➢ Many states have focused more on enrolling people that are currently living in community settings into HCBS programs than on transitioning individuals living in institutional settings back into the community. States have also continued to backfill institutional beds rather than closing them and reallocating institutional dollars to support individuals in their own homes and communities.

  o In the 11 states selected for follow-up, the increase in individuals served by HCBS was much larger than the decrease in individuals served in institutional settings.

    ▪ Colorado enrolled more than 5,300 additional people in HCBS at the nursing home level of care between 2008 and 2012, but the number of individuals in nursing facilities dropped by only 84 people over the same time period.

    ▪ Maryland increased the number of individuals served by HCBS programs at the nursing home level of care by 6,350 between 2008 and 2012, but decreased the number of people in nursing homes by only 394 people.

➢ When individuals are transitioned, it remains unclear whether they are transitioned to the most integrated setting possible or merely to a "less" institutional setting.

  o Only 14 states provided information on the actual number of transitions from institutions to an individual's own home, although the Chairman specifically requested this information.

  o Most states reported information on transitions more broadly, such as transitions to the "community," "integrated settings," or "HCBS setting," although they did not provide any clarification as to what these settings encompass.

  o Each state defines specific settings very differently.

    ▪ Hawaii and Minnesota defined a "home" as including being homeless, residing in a car, or living in a developmental disability home.

    ▪ Group home definitions are equally varied. In Texas, there are roughly two dozen types of homes, houses, centers, and other facilities that qualify as group homes.

    ▪ Regulations and definitions of "assisted living" settings also vary widely among states. Such facilities can range in size from a small residential house to a very large facility that provides services to hundreds of residents.

  o The Centers for Medicare & Medicaid Services (CMS) issued a proposed rule that clearly defines whether a setting is home or community-based, including access to the greater

community, opportunities for employment, protection of privacy and freedom from restraint, and independence in all life choices.

- Many states' *Olmstead* implementation efforts have not involved meeting specific benchmarks that are designed to transition people with all types of disabilities out of institutions and into the most integrated setting in a way that is cost-effective.

- No clear reporting system for HCBS programs exists to make it possible to analyze and compare how effectively states are meeting the *Olmstead* mandate.

Recommendations

- Congress should amend the ADA to clarify and strengthen the law's integration mandate in a manner that accelerates *Olmstead* implementation and clarifies that every individual who is eligible for LTSS under Medicaid has a federally protected right to a real choice in how they receive services and supports.

- Congress should amend the Medicaid statute to end the institutional bias in the Medicaid program by requiring every state that participates in the Medicaid program to pay for HCBS, just as every state is required to pay for nursing homes, for those who are eligible.

- State and federal efforts should focus on helping people live in their own homes. Virtually all people with disabilities can live in their own apartment or house with adequate supports. Accordingly, for virtually all people with disabilities, the most appropriate integrated setting is their own home.

- Congress should require clear and uniform annual reporting of the number of individuals served in the community and in institutions, together with the number of individuals transitioned and the type of HCBS living situation into which they are transitioned.

- States should more fully examine the enhanced federal funding available under new federal programs designed to encourage states to transition more individuals into community-based settings and shift away from waivers, which allow states to set caps on the number of individuals served. Other federal programs – including the Community First Choice Option (CFC), the Balancing Incentives Program (BIP), and the 1915(i) option—provide significant additional federal resources in exchange for requiring the state to serve all of the eligible populations. Congress and CMS should help states to conduct analyses of the unmet need in individual states.

- CMS should finalize its proposed rule defining what type of setting qualifies as home and community-based.

- DOJ should expand its *Olmstead* enforcement efforts, to include investigations of segregated employment settings for individuals with disabilities and the inappropriate placement of young people with disabilities in nursing homes, especially in states that are in the bottom quartile of spending on HCBS and/or for discreet subpopulations.

- CMS, the Administration on Community Living at the Department of Health and Human Services (HHS), the Office for Civil Rights at HHS, the Department of Housing and Urban Development (HUD), the Civil Rights Division at the Department of Justice (DOJ), the National Council on Disability (NCD), and the National Institute on Disability and Rehabilitation Research should create a high-level interagency task force within six months of the issuance of this report on *Olmstead*

implementation and should deliver a consistent message to states about their *Olmstead* obligations and the federally created tools that can help them comply with the decision.

- The task force described above should review and comment on proposed federal regulations and proposed subregulatory guidance that have the potential to impact *Olmstead* implementation.

- The task force described above should collaborate with the National Governors Association (NGA) and other appropriate entities to create a technical assistance program for states that helps them to develop and implement *Olmstead* plans.

- CMS should require incremental state spending goals for national Medicaid LTSS for 2015, 2020, and 2025 to ensure that the proportion of spending on HCBS continues to increase. Congress should increase the federal share of Medicaid expenditures for states that achieve these benchmarks and reduce the federal share for states that do not.

  - To help accelerate the states' progress, the Secretaries of HHS and HUD should write to the governors to inform them how they can best leverage the CFC Option, rebalancing initiatives, and federal housing subsidies as they provide services in the community.

- The Administration on Community Living at HHS and HUD should collaborate to develop and implement a national action plan to expand access to affordable, integrated, accessible, and "scattered site" housing for people with significant disabilities, consistent with the *Olmstead* decision.

- DOJ should create an *Olmstead* impact analysis instrument that can be used as states make significant changes in their Medicaid programs, including the following: implementation of managed care for LTSS, implementation of Medicaid expansions under the Affordable Care Act (ACA), and implementation of cuts in Medicaid and housing subsidies during periods of fiscal downturn.

- NCD should review the various federal tools that have been created to assist states in moving away from institutions and toward HCBS. NCD should make recommendations to the Administration and Congress that will make it easier for state legislatures and Medicaid officials to understand their options, and to reward states that are proactive and avoid rewarding states that have been dragging their feet on *Olmstead* implementation.

  - The NCD review described above should include recommendations to clarify the federal definition of "home and community-based" and to create a consolidated, streamlined federal reporting mechanism that would enable states to receive apples-to-apples comparisons with other states and allow federal officials and stakeholders to have timely, accurate information about key indicators in *Olmstead* implementation.

Introduction

June 22, 2013, marked the fourteenth anniversary of the United States Supreme Court's landmark decision *Olmstead v. L.C.*, which put states on notice that unnecessary segregation of individuals with disabilities is a violation of the Americans with Disabilities Act (ADA) of 1990. The ruling was hailed as the disability civil rights equivalent to *Brown v. Board of Education*, which ordered the desegregation of the nation's public schools. In general, the ruling promised individuals with disabilities services in the most integrated setting appropriate to their needs. For most people with disabilities, the most integrated setting appropriate is their own home. In addition, individuals with disabilities have a better quality of life in community settings.[1] Not surprisingly, individuals with disabilities prefer to use such services to live at home when provided the option to do so.[2] Previous testimony before this Committee illustrates why this option is so important:

> Two years ago, I entered the hospital because of seizures. As a result, I was placed in a nursing facility for 24/7 care because of my inability to walk. My healthcare providers did not feel because of my disability I was able to care for myself. I lived at Citizens Nursing Home, a county owned facility. Citizens Nursing facility is no different from other nursing homes. I had a horrible experience living there. It was depressing being in a place that was mostly older people. I had no one to talk to that I could relate with. I didn't like how I was cared for or how others were cared for. They treated me like a baby. They told me when to eat, sleep, and smoke. I had no time that was private or could be on my own. The small space given to me as a bedroom was small and confining. It was more like a hospital room. You have to share it with someone else. You didn't have your own things. There was no privacy, people in and out of your room, all day and all night. Your personal belongings are not safe. Things like electronics, food, and money are stolen. You hear residents screaming all night long. It was not clean. The floors and bathrooms had urine all over them. They didn't give you the therapy to get better. I just sat and stagnated, day after day. I had reached my limit and felt that I had to get away from there. I could not take living there any longer. I was totally disgusted with institutional life. Because of the Medicaid waiver program and Money Follows the Person, I have my own privacy and freedom to come and go as I please. I am not locked down like I am in a cage. I get to eat what I want to eat. That first hot dog was the best meal I had ever had. I can eat what I want and when I want to. I am now able to get rehabilitation so I can build my legs up to be able to walk again. I came out of a nursing home using a wheelchair and now, most of the time, I can use just my walker. It is my hope to be able to walk without assistance. My number one goal is to be able to go back to work part time. I will never go back to a nursing home. I will disappear if someone tries to put me back in a nursing home.
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> - *Excerpts from the testimony of Jeffrey Knight, consumer representative of the Maryland Money Follows the Person Program, Before the Senate Health, Education, Labor, and Pensions Committee, June 22, 2010*

> I lived in institutions all of my childhood. I was a resident of first DC Village and then in 1966 I went to Forest Haven, DC's institution for people with intellectual disabilities. My wife, brother and sister also lived at Forest Haven. For many years, no one told me that I had a brother and sister. We weren't told that we were related. In the institution, I didn't get to think for myself. The staff thought for me and made all of my decisions. For a long time, no one expected anything of me. I got to know some good staff and some really bad staff. I witnessed abuse, especially of people with severe disabilities. When I lived in the institution, no one would have believed that I could have the life I have today – married with a son and granddaughter, a good

job for 35 years, a driver's license and car, and opportunities to speak on behalf of Special Olympics International, which has taken me to places like Johannesburg. It's important to have people believe in you and to expect that you're going to succeed. People need to have high expectations for people with disabilities because then they'll give them opportunities to learn and grow. People don't grow in places like Forest Haven and in other institutions.

- *Excerpts from the testimony of Ricardo Thornton, Sr., Resident of the District of Columbia, Before the Senate Health, Education, Labor, and Pensions Committee, June 21, 2012*

Since the *Olmstead* decision, we have seen a dramatic rebalancing of state spending away from institutional settings in favor of home and community-based services (HCBS). The proportion of Medicaid LTSS spending on HCBS programs has increased from 20 percent to 50 percent since 1995. However, nationwide spending data does not tell the entire story. HCBS are fragmented between states and within states, and coverage for certain individuals with disabilities lags behind others. Specifically, a state needs to serve several distinct populations of individuals with disabilities: among others, people with physical, intellectual and developmental, and/or mental health disabilities; the elderly; and individuals with brain injuries. Because states need flexibility to serve these populations, the federal government has offered a variety of options to provide HCBS, including multiple new options created by the Patient Protection and Affordable Care Act (ACA).

Following a hearing last year before this Committee to assess the progress that had been made to implement the *Olmstead* decision, Chairman Tom Harkin sent letters to the Governors of all 50 states requesting information on HCBS. The purpose of the Chairman's request was to clarify whether states are ensuring that all populations of individuals with disabilities have the opportunity to live independently, while also providing the necessary services and supports in a cost-effective manner. To that end, the Chairman asked six specific questions to gather information about different aspects of the *Olmstead* initiative:

1) For each year from fiscal year 2008 to present: the number of people who moved from nursing homes, intermediate care facilities (ICFs) for individuals with intellectual or developmental disabilities, long-term care units of psychiatric hospitals, and board and care homes (often called adult care homes or residential health care facilities), to living in their own home, including through a supportive housing program.

2) The amount of state dollars that will be spent in this fiscal year serving individuals with disabilities in each of these settings: nursing homes, ICFs for individuals with intellectual or developmental disabilities, board and care homes, psychiatric hospitals, group homes, and their own homes, including through a supportive housing program.

3) For each year from fiscal year 2008 to present, the extent to which your state has expanded its capacity to serve individuals with disabilities in their own homes, including through a supportive housing program, along with the amount of state dollars spent on the expansion (which may include reallocated money previously spent on segregated settings) and the specific nature of the capacity added.

4) The contents of your state's *Olmstead* plan for increasing community integration and a description of the strategic planning process used to create it, as well as any revisions that have been made since its creation, the extent to which it incorporates any of the new tools created by the federal government to support home and community-based services, and the extent to which you have been successful in meeting any quantifiable goals identified within it.

5) Any policy recommendations you have for measures that would make it easier for your state to implement *Olmstead*'s integration mandate effectively and take advantage of new available federal assistance.

6) Any successful strategies that your state has employed to implement *Olmstead* effectively, particularly strategies that could be replicated by another state or on a national scale.

The Chairman received substantive responses from 31 states: Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, New Mexico, New York, Oregon, Rhode Island, South Dakota, Tennessee, Texas, Vermont, Virginia, Washington, West Virginia, Wisconsin, and Wyoming. In addition, both Mississippi and New Hampshire sent letters declining to provide a substantive response due to pending litigation related to the *Olmstead* decision. A compilation of all 33 state responses is available on our website. To supplement the information contained in the state's responses, Committee staff held follow-up discussions with 11 states: Arizona, California, Colorado, Connecticut, Iowa, Maryland, Minnesota, New York, Tennessee, Texas, and Washington. The Committee selected these states for follow-up based on several criteria, including geographic diversity, number and types of programs used, spending on programs, length of time in programs, and population in programs. The follow-up discussions included requests for additional information about spending, as well as broad questions related to the cost-effectiveness of various HCBS programs. Committee staff also reviewed existing reports on state spending on HCBS and consulted with stakeholders involved in *Olmstead* advocacy and implementation.

Seventeen states did not respond in any way to the Chairman's letter, despite repeated requests to do so. These states are Florida, Georgia, Idaho, Indiana, Kansas, Louisiana, Maine, Montana, Nevada, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, and Utah. Their failure to respond creates the impression that these states are not prioritizing the integration mandate of the ADA.

With respect to the states that did respond, the Chairman generally found that many state leaders and Medicaid directors are working hard to provide more HCBS in an era of rising costs and growing populations. However, most states continue to approach community living as a social welfare issue and not as a civil rights issue. With few exceptions, state leadership appears not to view the provision of HCBS as a means to guarantee that individuals with disabilities are able to exercise their civil rights as citizens by receiving supports that allow them to make their own decisions and fully participate in the life of their communities. Much of the problem appears to be based on concerns about adopting options that require a state to serve all individuals eligible for a particular set of services. An additional problem is a continued focus on providing care in settings that are "less institutional" but also are not the most integrated setting. These settings do not fully realize the integration mandate of providing individuals with disabilities the option to live at home. Finally, it is very difficult to assess the states' progress because of a lack of consistent classification, tracking, and reporting of both eligible populations and populations served.

Other issues confronting state leaders include ongoing financial crises at the national and state levels that have often led states to cut HCBS, even though they will typically pay more for individuals who are forced into institutional settings as a result. States are turning to Medicaid managed care to control LTSS costs. Although managed care organizations can make budgeting more predictable, there is little definitive evidence about whether they actually save money or improve outcomes for individuals with disabilities. Further, states must contend with rising expenses for those individuals who are "dual-eligible"— those who are covered by both Medicare and Medicaid. Poor coordination between the two

programs has led to inefficient delivery of services and confusion among program recipients and providers alike. A quality plan for *Olmstead* implementation should help to overcome these challenges. State leaders should approach *Olmstead* implementation efforts by first focusing on the concept of the most integrated setting, and then setting reasonable timeframes and measurable goals to ensure that all individuals with disabilities are offered the most integrated setting. While many of the states have laudable paper plans, they lack enforceable benchmarks and targets directed at consistently transitioning people with all types of disabilities out of institutional settings and into living situations that allow individuals to exercise the autonomy and the rights guaranteed by the Constitution and the ADA in a way that is cost-effective for that state.

This report provides an overview of the states' ongoing struggle to fulfill the community living promise of the ADA and *Olmstead*. Section 1 includes information on terminology used throughout the report, background on HCBS generally, and a description of the *Olmstead* decision and its subsequent impact on federal and state activities. Section 2 explores the responding states' experiences with federal HCBS tools. Section 3 provides information on the states' spending on institutions, HCBS, and the populations served by HCBS. Section 4 analyzes the states' progress in moving individuals with disabilities into the community. Section 5 discusses the states' *Olmstead* planning efforts and suggestions for effective *Olmstead* implementation. Finally, section 6 sets forth the Committee's recommendations for moving forward.

Section 1: Background

This section provides background on the following: (1) terminology and definitions used throughout this report, (2) information on how HCBS and institutions are covered by Medicaid and managed care organizations, (3) a description of the ADA and the *Olmstead* decision, (4) *Olmstead* planning guidance, (5) *Olmstead* enforcement efforts, (6) efforts to rebalance spending on institutions and HCBS, and (7) ongoing challenges to community integration.

Terminology and Definitions

Under the ADA, an individual with a disability is a person who (1) has a physical or mental impairment that substantially limits one or more major life activities, (2) has a record of such an impairment, or (3) is regarded as having such an impairment. Clearly, this definition is very broad, and states need to serve several distinct populations of individuals with disabilities including, among others, people with physical, intellectual and developmental, and/or mental health disabilities; the elderly; individuals with brain injuries; individuals with HIV; and children with disabilities. As a result, there are a variety of terms used to describe the challenges faced by these populations, the services they need, and the levels of care required. Throughout this report, we use the following most frequently:

Intellectual Disabilities (ID): Refers to a group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and routines, or social interactions. ID originates before the age of 18 and may result from physical causes, such as autism or cerebral palsy, or from nonphysical causes, such as lack of stimulation and adult responsiveness.

Developmental Disabilities (DD): Refers to a severe, long-term disability that can affect cognitive ability, physical functioning, or both. These disabilities appear before age 22 and are likely to be lifelong. The term "developmental disability" encompasses ID but also includes physical disabilities. Some DDs may be solely physical, such as blindness from birth. Others involve both physical and intellectual disabilities stemming from genetic or other causes, such as Down syndrome and fetal alcohol syndrome.

Mental Illness (MI): A health condition that affects a person's thinking, feelings, or behavior and causes the person distress and difficulty in functioning.

Long-Term Services and Supports (LTSS): LTSS include many types of health and health-related services for individuals of all ages who have limited ability to care for themselves because of physical, cognitive, or mental disabilities or conditions. [3]

Activities of Daily Living (ADL): Individuals needing LTSS have varying degrees of difficulty performing these activities, which include bathing, dressing, toileting, and eating, without assistance.

Instrumental Activities of Daily Living (IADL): Individuals needing LTSS may also have difficulties with these activities, which include preparing meals, housekeeping, using the telephone, and managing money.

Home and Community-Based Services (HCBS): HCBS refer to a wide range of services and supports to help individuals remain in their homes or live in a community setting, such as personal care services to provide assistance with ADLs or IADLs, assistive devices, respite care for caregivers, assertive

community treatment (ACT), crisis services, supported employment, peer supports, and case management services to coordinate services and supports that may be provided from multiple sources.

Nursing Facility (NF): These facilities primarily provide three types of services: (1) skilled nursing or medical care and related services; (2) rehabilitation needed due to injury, disability, or illness; and (3) long-term care to provide health-related care and services (above the level of room and board) not available in the community, needed regularly due to a mental or physical condition.

Intermediate Care Facility (ICF, ICF/MR, ICF/ID, and ICF/DD): These facilities provide health-related services to individuals who do not require the degree of care or treatment given in a hospital or NF, but who (because of their mental or physical condition) do require care and services. Federal law and regulations use the term "intermediate care facilities for the mentally retarded," or "ICF/MR." CMS prefers to use the accepted term "individuals with intellectual disability" instead of "mental retardation" and typically uses the acronym "ICF/ID" to characterize these facilities. Many states have chosen to do the same or simply use "ICF." Other states also have ICFs for individuals with DDs, or "ICF/DD." For purposes of this report, we will defer to the characterization and acronym used by each state.

Level of Care: Level of care refers to the amount of assistance an individual needs—for example, assistance with ADLs and IADLs. An individual may require HCBS that provide an "NF level of care" or an "ICF level of care."

Medicaid and Managed Care Coverage of LTSS

Medicaid—the joint federal-state financing program for health care services for certain low-income individuals—is the nation's primary payer for LTSS. At the federal level, CMS is responsible for overseeing the design and operation of states' Medicaid programs. The amount of federal funds states receive is determined by a statutory formula—the Federal Medical Assistance Percentage (FMAP). Under the FMAP, the federal government pays a share of Medicaid expenditures based on each state's per capita income relative to the national average. The FMAP for federal fiscal year 2012 for states ranged from about 50 percent to 74 percent. To receive their federal matching dollars for services provided to Medicaid beneficiaries, each state must submit a state Medicaid plan for consideration, review, and approval by CMS. A Medicaid state plan must describe the scope of a state's Medicaid program, including a list of eligibility categories and standards and the services covered. As part of their plans, states must cover a set of mandatory services, including those provided by primary and specialty care physicians. Since the Medicaid program was first established in 1965, states have been required to cover NF care for all Medicaid beneficiaries age 21 and older. States are also required to offer HCBS through the Home Health benefit to all individuals entitled to NF coverage under the state's Medicaid plan. Services that may be covered under this benefit include nursing, medical equipment, and therapeutic services. Coverage of other HCBS is optional.

States may elect to cover HCBS through optional state plan benefits. For example, states have the option to offer the Personal Care Services (PCS) benefit, which covers assistance with ADLs and IADLs, furnished either at home or in another location.[4] Numerous changes to federal Medicaid law since the program's inception have expanded states' options for covering HCBS under their state plans, including new options created by the ACA. Specifically, the ACA created the Community First Choice Option (CFC), which provides an increased FMAP for states choosing to cover a package of personal care services for eligible individuals, and the Balancing Incentives Payment Program (BIP), which provides an increased FMAP through 2015 for states that rely heavily on institutional facilities to rebalance their LTSS systems toward more home and community-based care. The ACA also amended two existing Medicaid HCBS options: the §1915(i) state plan option and the Money Follows the Person

program (MFP). The §1915(i) option allows states to cover a package of HCBS programs for a targeted group of people under their state Medicaid plan, while MFP is a demonstration grant program to support states' transition of eligible individuals who want to move from institutional settings back to the community.

For people with mental illnesses, the Rehabilitation Option is the primary source of Medicaid funding for community services. This very broad option covers "rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care."[5] Rehabilitation services include "any medical or remedial services recommended by a physician or other licensed practitioner of the healing arts, within the scope of his practice under State law, for maximum reduction of physical or mental disability and restoration of a recipient to his best possible functional level." Nearly all states utilize the option to cover some type of community mental health services. States can use the rehabilitation option to cover a variety of services that are essential to enable people with disabilities to be integrated into their communities, including intensive case management, mobile crisis services, assertive community treatment for people with psychiatric disabilities, skill training that supports stable housing and employment, and peer support services.[6] Individuals in all fifty states also have access to targeted case management services.[7] These services include assessment of the individual to determine service needs, development of a specific care plan, referral and related activities to help the individual obtain needed services such as employment supports, and monitoring and follow-up to ensure that the care plan is effectively implemented and adequately addresses the needs of the eligible individual.[8] States may also provide targeted case management services to individuals in any defined location of the state or to individuals within targeted groups specified in the state plan.[9]

In addition to the options listed above, states can use waivers, such as §1915(c) waivers and §1115 research and demonstration waivers, to provide services not covered by Medicaid to designated populations who may or may not otherwise be eligible for Medicaid services. In this way, states "waive" the traditional eligibility and service requirements of Medicaid and create new rules for a specific population of citizens. Generally, waivers must be, on average, equally or more cost-effective than the average cost of institutional care. If approved, a waiver may allow a state to limit the availability of services geographically, target services to specific populations or conditions, and cap both the number of individuals served and overall expenditures—actions that are generally not otherwise allowed under the federal Medicaid law, but which may enable states to control costs.

States are also turning to Medicaid managed care to cover LTSS costs. Under Medicaid managed care, states contract with health plans and prospectively pay the plans a fixed monthly rate per enrollee to provide or arrange for most health services. These contracts are known as "risk" contracts because plans assume the risk for the cost of providing covered services.[10] The shift to introducing or expanding managed care is driven by states' predictions that it will lower costs or at least create a more stable, predictable growth rate. Rather than paying multiple entities various fees per service, states are increasingly choosing to reimburse one entity at a fixed rate per person, with the expectation that quality and access will not be compromised. Because of this fixed rate, managed care organizations (MCOs) are given incentives to provide the most efficient care possible, by limiting their financial risk and maximizing their potential profit. Managed care for LTSS grew significantly between 2004 and 2012: the number of states with such programs doubled from eight to 16, and the number of persons receiving LTSS through managed care programs increased from 105,000 to 389,000.[11]

Using MCOs for LTSS could expand consumers' access to HCBS. MCOs can also increase coordination, stabilize state costs, and make budgeting more predictable. However, placing responsibility for Medicaid LTSS with MCOs is a dramatic shift in policy and practice. Research to date indicates that relative to fee-for-service programs, some managed care programs have reduced the

use of institutional services. However, whether managed care reduces institutionalization and promotes people being served in the most integrated setting depends on how the program is structured. For example, carving out institutional services from managed care plans does little to reduce institutionalization. Additionally, there is little definitive evidence as to whether managed care saves money or how it affects outcomes for consumers.[12] Further, there is no national consensus on how best to make this change; emerging state proposals are very diverse in their approach to incorporating LTSS into managed care. Finally, consumer advocates increasingly fear that consumers will face disruptions in LTSS under managed care. Specifically, although MCOs have experience delivering acute health care services, most simply do not have experience with or expertise in providing HCBS to this population.

The Americans with Disabilities Act and the *Olmstead* Decision

The ADA was intended to help fully integrate people with disabilities into American life.[13] Specifically, the ADA prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation.[14] In Title II of the ADA, which proscribes discrimination in the provision of public services, Congress specified that:

> [N]o qualified individual with a disability shall, by reason of such disability, be excluded from participation in, or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by such an entity. [15]

Congress authorized the Department of Justice (DOJ) to issue regulations implementing Title II's discrimination proscription. One such regulation requires a public entity to administer programs, services, and activities in the most integrated setting appropriate to the needs of individuals with disabilities.[16] Specifically, this means a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible. To accomplish this, public entities are required to make reasonable modifications to their policies, practices, and procedures when necessary to avoid discrimination. Importantly, an effective system of LTSS is needed to assists persons with disabilities and older adults to live independently in the community. LTSS are used by individuals of all ages with functional limitations and chronic illnesses who need assistance to perform routine daily activities.

The Supreme Court also affirmed the ADA's "integration mandate." In *Olmstead*, Lois Curtis and Elaine Wilson were voluntarily admitted to a Georgia state psychiatric hospital, where they were held for treatment for intellectual and psychiatric disabilities. Following the women's treatment—one for schizophrenia and the other for a personality disorder—mental health professionals concluded that each was ready to move to a community-based program. However, both women remained confined in the institution for several years after they were determined ready to be discharged. Seeking placement in community care, Ms. Curtis filed suit under the ADA for release from the hospital. Specifically, the suit alleged that Georgia had violated Title II of the ADA in failing to place them in a community-based program once their treatment professionals had determined that such placement was appropriate.

On June 22, 1999, the United States Supreme Court held that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA.[17] The Court held that public entities must provide community-based services to persons with disabilities when: (1) such services are appropriate, (2) the affected persons do not oppose community-based treatment, and (3) affording community-based services would not fundamentally alter a state's service system.

The Court explained that its holding "reflects two evident judgments."[18] First, "institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life."[19] Second, "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."[20]

Olmstead Implementation Guidance

Since the Court's decision, the federal government has issued guidance to help states implement *Olmstead*. In 2011, DOJ issued guidance stating in part that a public entity's plan for implementing *Olmstead*:

> must have specific and reasonable timeframes and measurable goals for which the public entity may be held accountable, and there must be funding to support the plan, which may come from reallocating existing service dollars. The plan should include commitments for each group of persons who are unnecessarily segregated, such as individuals residing in facilities for individuals with developmental disabilities, psychiatric hospitals, nursing homes and board and care homes, or individuals spending their days in sheltered workshops or segregated day programs.[21]

As this guidance suggests, there is no "one-size fits all" approach to developing an *Olmstead* plan. To comply with *Olmstead* successfully, each state needs to focus on the actual needs of its own communities and ensure that whatever measures it adopts are implemented effectively. To that end, a group of 25 major national disability rights organizations, including state mental health directors and state directors of DD services,[22] have espoused a number of key principles for community integration for people with disabilities:

- Individuals with disabilities should have the opportunity to live like people without disabilities. They should have the opportunity to be employed, have a place to call home, and be engaged in the community with family and friends.

- Individuals with disabilities should have control over their own day, including which job or educational or leisure activities they pursue.

- Individuals with disabilities should have control over where and how they live, including the opportunity to live in their own apartment or home. Living situations that require conformity to a collective schedule or that restrict personal activities limit the right to choose.

- Individuals with disabilities should have the opportunity to be employed in non-segregated, regular workplaces. Virtually all individuals with disabilities can be employed and earn the same wages as people without disabilities. When needed for such employment, they should have access to supported or customized employment. They should be afforded options other than sheltered work, day treatment, clubhouses, and other segregated programs.

- Virtually all individuals with disabilities can live in their own home with supports. Like people without disabilities, they should get to decide where they live, with whom they live, when and what they eat, and who visits and when.

- To this end, individuals with disabilities should have access to housing other than group homes, other congregate arrangements, and multi-unit buildings or complexes that are primarily for people with disabilities. They should have access to "scattered site" housing, with ownership or control of a lease. Housing should not be conditioned on compliance with treatment or with a service plan.

- Individuals with disabilities should have the opportunity to make informed choices. They must have full and accurate information about their options, including what services and financial support are available in integrated settings. They should have the opportunity to visit integrated settings and talk to individuals with similar disabilities working and living in integrated settings. Their concerns about integrated settings should be explored and addressed.

- Government funding for services should support implementation of these principles. Currently, public funding has a bias toward institutionalization, forcing individuals to overcome myriad barriers if they wish to age in place and remain in their communities.

In addition to these principles, stakeholders identified some of the key elements of *Olmstead* compliance. The items below are not an exhaustive list of what is required for *Olmstead* compliance, but emerged from our discussions as important practices to ensure that individuals with disabilities are afforded meaningful opportunities to live in integrated settings.

- Ongoing efforts to educate residents of institutions about their options for living in integrated settings, including the services and financial support available if they choose to live in their own homes or apartments. These efforts are often called "in-reach."

- Providing opportunities for residents of institutions to visit integrated settings, such as "scattered site" supportive housing, and to speak with peers who live in those settings.

- Developing and using assessment tools that begin with the presumption that people with disabilities can live in their own homes and, for the rare circumstance in which that is not the case, identify what services a person needs that could not be provided in his or her own home.

- Developing sufficient housing and service capacity in the community so that residents of institutions have a meaningful opportunity to live in the most integrated setting appropriate.

- Ensuring that assessments of residents' needs are done when housing and services are actually or will soon be available.

Olmstead Enforcement Efforts

Appellate courts have generally rejected interpretations of *Olmstead* that would make it more difficult for plaintiffs to establish a *prima facie* case that the state has failed to fulfill the ADA's integration requirement.[23] Accordingly, they have held that a *prima facie* violation of the ADA's integration requirement may exist even absent allegations that (1) the state placed or held the qualified individuals in an institution, (2) the state uses disability-specific criteria to decide who is eligible for community-based services, or (3) the plaintiffs are eligible to receive the requested services under state law.[24] Typically, states defend their non-compliance with *Olmstead* on one of three grounds: (1) they have a "comprehensive, effectively working plan" that meets the standard of the *Olmstead* plurality, (2) budget constraints prevent them from developing and implementing such a plan, or (3) the services sought would be "new" and therefore require a fundamental alteration of the state's program.[25] Only in some

instances have courts found that a state was sufficiently committed to deinstitutionalization because of these grounds.[26]

Over the past several years, the Civil Rights Division of DOJ has actively sought to enforce *Olmstead*, joining or initiating litigation to ensure that community-based services are provided. Specifically, the Division has been involved in more than 40 matters in 25 states.[27] Recent cases include landmark settlement agreements with Delaware, Virginia, and Georgia that will allow thousands of individuals with disabilities to receive services in community settings and that will serve as models of comprehensive agreements with other states. Another example is North Carolina, which recently entered into an agreement to transform the state's system for serving people with mental illness.[28] Under the settlement agreement, over the next eight years, North Carolina's system will expand community-based services and supported housing that promote inclusion and independence and enable people with mental illness to participate fully in community life.[29]

DOJ has also expanded its collaborations with other federal agencies, including the Departments of Health and Human Services (HHS), Housing and Urban Development (HUD), and Labor, recognizing that community integration can only be successful if people have access to necessary community services and housing.[30] According to HHS's Office of Civil Rights (OCR), during the period from August 1, 1999, through September 30, 2010, the office resolved 850 *Olmstead* cases.[31] Thirty-two percent of these cases were resolved after intake and review, 42 percent involved corrective actions to resolve civil rights issues, and only 26 percent found no civil rights violations.[32]

Efforts to Rebalance Spending on Institutions and HCBS

Since the *Olmstead* decision, the federal government has implemented several initiatives and approved a number of new tools for community integration.[33] Highlights include:

- The Deficit Reduction Act of 2005 authorized the MFP demonstration, which provides states with an enhanced federal medical assistance percentage for one year for each individual who meets program eligibility requirements and transitions from an institution to a qualified community setting.

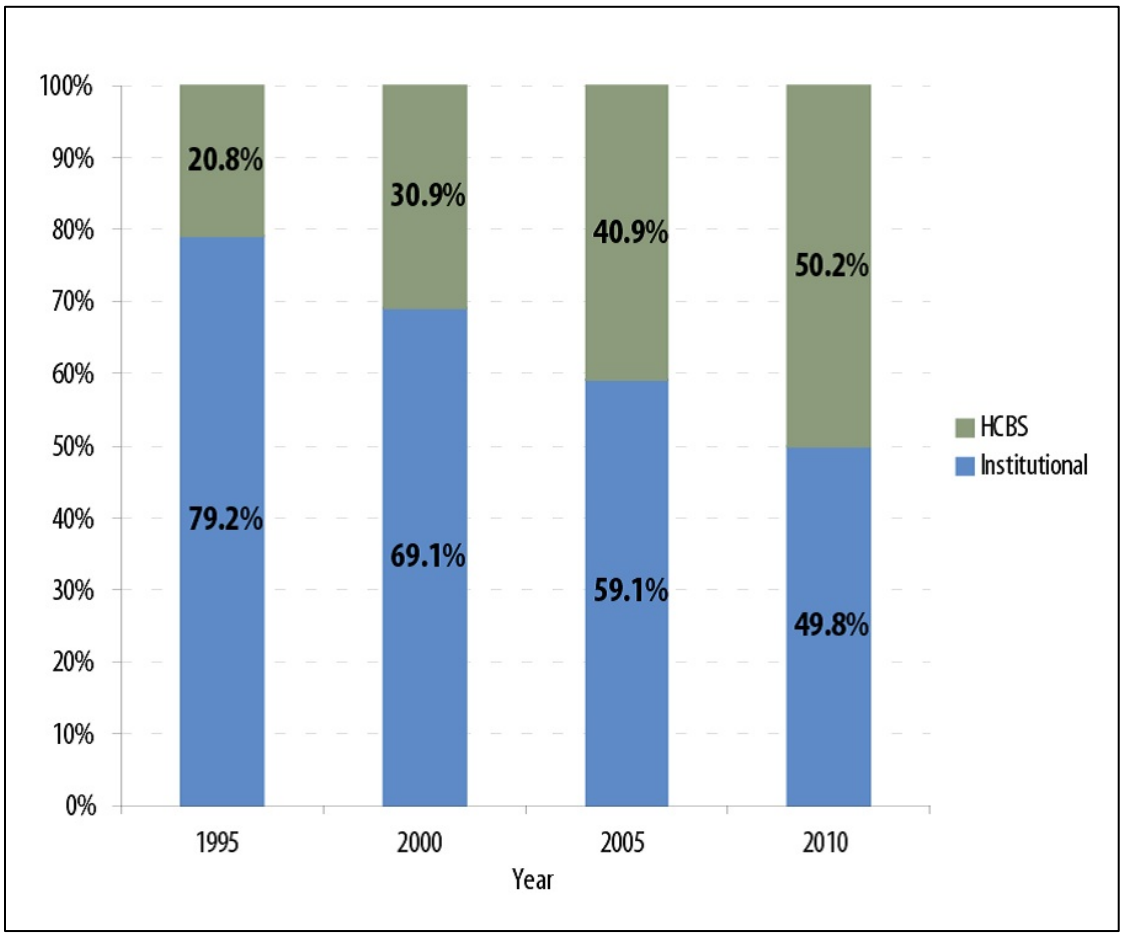
- In 2009, on the 10th anniversary of *Olmstead*, President Obama launched "The Year of Community Living," a new effort to assist Americans with disabilities. As a result of that effort, HHS implemented the Community Living Initiative to promote federal partnerships that advance the directives of the *Olmstead* decision. The Initiative is intended to develop and implement innovative strategies that increase opportunities for Americans with disabilities and older adults to enjoy meaningful community living.

- In 2010, the passage of the ACA provided a number of new funding opportunities and financial incentives to expand community-based LTSS systems. The ACA created two new options and revised two existing options for Medicaid home and community-based services: CFC, BIP, MFP, and the 1915(i) state plan option, respectively. The four Medicaid options for HCBS provide states with new incentives and flexibility to help increase the availability of services for Medicaid beneficiaries.

- In 2012, HHS created the Administration for Community Living (ACL) with the goal of increasing access to community supports and full participation, while focusing attention and resources on the unique needs of older Americans and people with disabilities.

As a result of these and other federal activities, states have been motivated to pursue "rebalancing" initiatives to move their LTSS systems away from a dependency on institutions and toward a system that embraces consumer choice and care in the home or community. Further, as shown in the following figure, the proportion of Medicaid LTSS spending on HCBS programs has increased over a 15-year period, while the proportion of spending on institution has decreased.

Proportion of Medicaid LTSS Spending, by Setting, 1995-2010

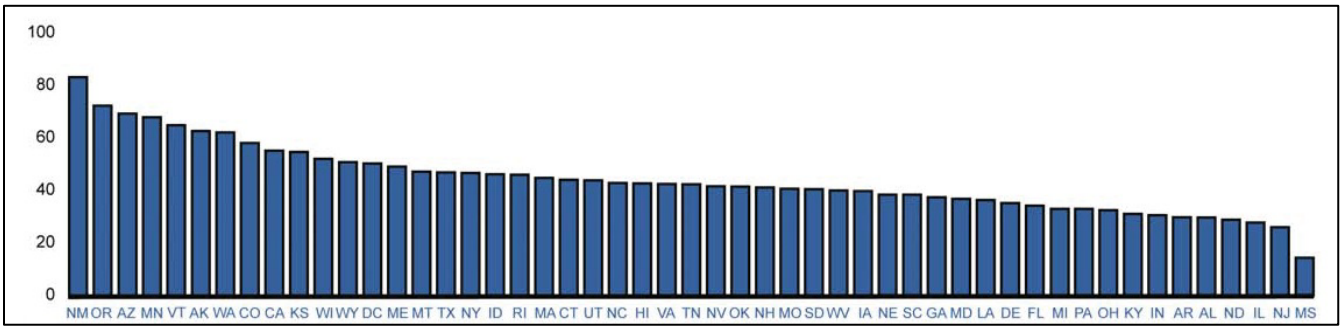


Source: CRS analysis of National Health Expenditure Account (NHEA) data obtained from the Centers for Medicare & Medicaid Services (CMS), Office of the Actuary, prepared November 15, 2011.

Ongoing Challenges to Integration

However, nationwide spending data does not tell the entire story. In fact, many studies have shown that spending on HCBS varies significantly *across* states. As shown in the figure below, the Government Accountability Office reported that in fiscal year 2009, the percentage of LTSS spending in HCBS varied from more than 80 percent to less than 20 percent, with the majority of states falling from between 60 to 30 percent.[34] Another study noted that although national per person spending on Medicaid HCBS averaged $15,371 in 2009, there was great variation among the states, ranging from $5,232 spent per person in Illinois to $35,378 in Tennessee.[35]

Variation in State Spending on HCBS as a Percentage of LTSS Spending, Fiscal Year 2009



Source: GAO analysis of CMS data.

Other studies and reports show a variety of obstacles to integration.

- Progress in rebalancing LTSS for older adults and persons with physical disabilities has lagged significantly behind rebalancing for individuals with ID/DD.[36]

- For people with aging-related physical and cognitive impairments, only six states spent more on HCBS than on institutions in 2009, and some states spent only a token proportion of the money for LTSS on HCBS.[37]

- Widespread inequities in access to Medicaid HCBS exist across states. Some groups, such as children and individuals with traumatic brain injury, mental illness, and HIV/AIDS, have limited or no access to HCBS.[38]

- A recently issued report noted that waiting lists for residential and community services demonstrate an unmet need: more than a quarter of a million people with ID/DD are on a waiting list for HCBS, almost double the number on waiting lists in 2007.39 Another study showed that in 2008, 38 states reported that 122 HCBS programs had waiting lists that totaled 393,096 people.[40]

- Medicaid consumers are often not given a choice of types of services and an opportunity to receive services in the most integrated setting, especially those individuals discharged from hospitals.[41]

- The number of programs within states creates confusion for consumers and the public, who often do not know what programs are available and how to access the programs.[42]

- As of 2009, more than 500,000 people with mental illnesses other than dementia lived in nursing homes,43 although studies show that nearly all of these individuals could live independently in the community with adequate supportive services.[44]

- Despite an initial flurry of activity following the Olmstead decision, reports indicate that enforcement efforts later slowed until the Justice Department began several years ago to do more assertive enforcement.[45]

- Advocates have noted that when progress in integration occurs, it is frequently in reaction to a lawsuit or unfavorable media coverage, rather than as an affirmation of civil rights.[46]

Section 2: States' Experiences with Federal HCBS Tools

In general, the responses that Chairman Harkin received demonstrate that states have many options and flexibility if they are committed to providing HCBS to individuals with disabilities. Specifically, states can use the following:

1) The PCS option, which covers assistance with the activities of daily living at home and do not require participants to meet an institutional level of care requirement.

2) The §1915(i) option, which allows states to offer a variety of HCBS as a Medicaid state plan benefit using individuals' income level as a criteria for service. The ACA revised the option to disallow program caps.

3) CFC, which was created by the ACA and designed in part to encourage states that currently do not have the PCS option to add such services to their Medicaid programs through increased incentives.

4) BIP, which was also created by the ACA and provides incentives through 2015 for states that rely heavily on institutional facilities to rebalance their LTSS systems toward more home and community-based care.

5) The MFP grant program, which is an important start-up tool and provides incentives to states to move people currently in nursing homes and other institutional settings to the community.

6) §1915(c) waivers, which allow states to create an HCBS plan for a capped number of individuals needing an institutional level of care, provided that the plan is cost-neutral.

7) §1115 Research and Development waivers, which give states authority to approve experimental, pilot, or demonstration projects for a limited number of individuals.

8) The Rehabilitation Option, which is the primary source of Medicaid funding for community services for people with mental illnesses and covers services such as intensive case management, mobile crisis services, and assertive community treatment for people with psychiatric disabilities.

Studies have shown that the majority of Medicaid spending on non-institutional LTSS continues to occur through HCBS waivers, which allow states to use a broad range of cost-containment strategies.47 The state responses that the Chairman received confirm this finding. For example, 28 states reported using §1915(c) waivers to provide HCBS, and most have multiple §1915(c) waivers targeted to a variety of different populations, such as persons living with HIV and brain injuries. The responses also show that states generally prefer options that allow them to cap the number of individuals served. As a result, states vary in their willingness to implement the new options created by the ACA, even though these options provide incentives to states through increased financial support. For example, many states commented that the CFC and 1915(i) options would not work for them because of the perceived financial risk arising from the inability to limit the option to a set number of individuals. The concern is that large numbers of people who previously received help from family members and did not seek institutional services might sign up for the more desirable non-institutional services, thus creating uncertainty about the potential total cost of HCBS in an environment where these services are more readily available.

Even if there are perceived uncertainties related to costs, states cannot use such concerns as an excuse for failing to fulfill the community living promise of the ADA. Instead, states must take into account the values of independence and community participation for people with disabilities of all ages.[48] States should also consider the significant cost savings achieved through reallocating institutional funding to community services, including the reduction in costs over time as community services foster greater independence (in contrast to institutional services that perpetuate dependence). Studies have shown that HCBS saves money. One study found that during a decade of expanding HCBS in many states, those states with a high proportion of spending on HCBS spent no more on LTSS than other states.[49] Another study found that states with well-established HCBS saved money on LTSS over time compared to states spending a low proportion on HCBS.[50] Other studies have noted that states appear to be able to make changes when they are given adequate support and incentives by the federal government,[51] such as through the enhanced FMAP associated with the new options created by the ACA.[52] In a state where large populations of people with disabilities are being cared for by family and other informal caregivers, it is important to note the costs associated with such a situation. These costs include reduced tax revenues from family members who are not part of the labor force, health care expenditures associated with informal caregivers who get injured while they are providing care, and costs associated with unnecessary institutionalization when a family caregiver can no longer provide the care. The responding states' experiences with the various HCBS options[53] are discussed below:

Personal Care Services

PCS provides personal assistance with daily activities to people meeting the state's functional criteria for such need. The eligible population is generally very broad, but the services provided are often limited to a relatively small number of hours of help per week. As a result, PCS are typically less costly per participant than waiver options because benefits are more limited. PCS can be tailored by the state to cover ADLs and IADLs, and participants do not need to meet an institutional level of care criterion. However, PCS benefit must be available to all categorically eligible groups, and the normal FMAP allocation applies to these services.

According to recent reports, 32 states offered PCS as of 2008.[54] Eight states discussed their use of PCS in their response letters to the Chairman.[55] New Mexico considers the personal care option the "linchpin" of the state's Medicaid system; the "program is designed to improve the quality of life for those with disabilities and health conditions, and to prevent them from needing to enter nursing facilities." In addition, Washington reported that using PCS has been particularly successful in supporting and allowing "people to remain in their own homes or family homes."

Section 1915(i) Option

The §1915(i) state plan option was originally created by the Deficit Reduction Act of 2005.[56] This first incarnation authorized HCBS, including home health aides, respite care, and personal care, for Medicaid-eligible individuals with income less than 150 percent of the federal poverty level (FPL). The original option allowed states to cap the number of people serviced and required states to establish needs-based criteria for determining eligibility for services that are less stringent than the state's criteria for determining eligibility for institution. The ACA modified the §1915(i) option to expand the income level for eligibility and authorized additional benefits. However, the modification disallowed program caps and required renewals every five years. The §1915(i) option does not provide states with financial incentives in the form of enhancements to the FMAP.

Several states added a §1915(i) option to the state Medicaid plan before the changes made by the ACA.[57] Four states have submitted and/or received approval for state plan amendments since the ACA

changes took effect,[58] and several additional states mentioned that they were considering this option.[59] Connecticut and Kentucky currently use §1915(i) to provide targeted services to individuals with DD and elderly individuals. Five states commented that §1915(i) was a good way to provide services to individuals with mental illness.[60] Massachusetts and Tennessee both expressed concerns regarding how the ACA revision to the option prevented states from limiting the program to a set number of individuals. Minnesota also suggested that "[t]echnical assistance, training, and fiscal frameworks for the implementation" would be helpful.

Community First Choice

The CFC state plan option was created by the ACA.[61] The proposed rule implementing CFC was issued on February 25, 2011.[62] The final rule was issued on May 7, 2012, although a supplemental proposed rule was issued on May 3, 2012, to clarify the definition of "home and community-based settings." CFC coverage must be provided statewide, and states cannot cap the program; all eligible persons must be served. However, eligibility is limited to include (1) all individuals with income that does not exceed 150 percent of the FPL, who are eligible for Medicaid and who require HCBS to remain out of institution and (2) all individuals with income greater than 150 percent of the FPL who are eligible for NF services under the state's Medicaid plan. For the first 12 months after CFC takes effect, states must maintain the same level of expenditures for CFC as they spent on PCS during the previous 12 months. CFC provides states with a six percentage point increase in their FMAP.

Given that the final rule was issued only a month before the Chairman sent his request to the states, it not surprising that only one state, California, reported that it had actually implemented CFC. Oregon recently implemented the option at the end of June and four other states reported that they were in the process of adopting the option.[63] New York indicated that a CFC amendment is pending, with a planned effective date of October 1, 2013. At least five states were still in the process of assessing whether the option was suitable.[64]

States offered a variety of comments on CFC. For example, even though its CFC state plan amendment is currently pending, Maryland expressed continued concern that the number of individuals eligible for the plan was unknown, and thus it was difficult to project the cost and potential expenditures. In contrast, Arizona reported that it believed that CFC offered a way to provide more self-direction opportunities to individuals with disabilities, and that CFC allowed the states to provide new services and supports than are currently available. Washington is considering the option for similar reasons, although it is concerned that the requirements for caregivers in CFC are different than those under its state laws. Arkansas mentioned cost-effectiveness and personal choice as motivating factors in its consideration of the option, and Minnesota stated that it hopes to use CFC in conjunction with other federal tools to transform LTSS to provide flexibility and self-determination to all of its beneficiaries.

Other states reported a conviction that the option would not work for them. For example, Iowa and Tennessee were concerned that CFC could not be limited to a set number of individuals and thus created a substantial financial risk. Alaska reported that it initially believed that CFC held promise but did not work for the state because of the final rule's restriction that all participants meet an institutional level of care. Therefore, if Alaska chose to implement the option, about 50 percent of the individuals currently enrolled in its existing Personal Care Attendant program would lose that service and, consequently, the state would be forced to administer two separate programs, each serving approximately 2,500 individuals. Hawaii said that the CFC was unnecessary given their existing HCBS. Wyoming is waiting on the final supplemental rule to be issued due to concerns about the rule's narrowly defined interpretation of "community," which will result in states having to limit funding to group residential programs and instead focus funding on independent living options.

Balancing Incentives Payment Program

BIP provides an enhanced FMAP to states that spent less than 50 percent of their Medicaid LTSS budget on HCBS. The FMAP enhancement is an additional five percent if the state spent less than 25 percent of its 2009 LTSS budget on HCBS and two percent if the state spent between 25 and 50 percent of its budget on HCBS. In addition, states must make three modifications to their Medicaid system by creating (1) a simplified application process, (2) conflict-free case management services, and (3) a core standardized assessment instrument. The program took effect on October 1, 2011, and the application window closes in August 2014. Based on 2009 LTSS spending data, 38 states were eligible for BIP because they spent less than 50 percent of their LTSS spending on HCBS. Only one state—Mississippi—spent less than 25 percent of its 2009 LTSS budget on HCBS.

Of the 31 states that provided substantive responses to the Chairman's letter, 20 are eligible for BIP because they spent less than 50 percent of their 2009 LTSS spending on HCBS.[65] However, only seven of the responding states indicated that they had adopted BIP or were preparing applications: Arkansas, Connecticut, Illinois, Iowa, Maryland, Missouri, and New York. Specifically, Iowa and Missouri were awarded BIP funding in July 2012, and Connecticut was awarded BIP funding in late 2012. Maryland and New York have also been awarded funding. Missouri and Iowa both commented that the grant will help the development of community infrastructure and strengthen community-based services. Illinois and Arkansas are preparing applications for BIP. Illinois noted that the program will provide the state with enhanced funding to continue its rebalancing efforts and strengthen its community capacity, while Arkansas commented that it sees BIP as a component of its plan to revise how it pays for Medicaid completely.

Only three other states discussed BIP in their responses. Specifically, although Hawaii was eligible for BIP, it commented that the program was unnecessary because the state "already provide[s] comprehensive HCBS under [a] 1115(a) waiver" and "has been extremely successful in rebalancing long-term care service delivery and expanding access to and receipt of HCBS." Tennessee reported that the two percent increase in FMAP was "not substantial enough to offset the significant administrative burden that will be required to achieve program goals." Michigan is still reviewing BIP to determine whether it is a useful additional resource.

Of the 19 states that did not provide substantive responses to the Chairman's letter, 18 are eligible for BIP.[66] However, only six are currently participating in the program.[67]

Money Follows the Person

MFP is a demonstration project originally passed as part of the Deficit Reduction Act of 2005.[68] The program was designed to "[i]ncrease the use of home and community-based, rather than institutional, long-term care services" by providing additional Medicaid funding to pay for transitioning individuals from an institutional setting into the community. The funding is an enhanced FMAP of up to 90 percent applied to HCBS expenditures for 12 months after an individual has transitioned into the community. The initial funding was scheduled to be dispersed from 2007 to 2011, but, in 2010, the ACA provided additional funds to extend the demonstration project through 2016. Each state's MFP consists of a transition program, to identify Medicaid beneficiaries living in institutions who wish to live in the community and then help them do so, and a rebalancing program, for states to make system-wide changes to support Medicaid beneficiaries with disabilities living and receiving services in the community.

The popularity of this program is reflected in the states' responses. Eighteen states reported applying for and receiving MFP grants as part of the first round in 2007,[69] and eight states reported receiving MFP grants as part of the second round in 2011.[70] In addition, two states have announced pending planning grants for MFP, [71] which allow states to use federal money to build an infrastructure that supports MFP.

The states that have adopted MFP report very favorably on the program, calling it "a key tool in expanding access to HCBS for individuals with disabilities" and "instrumental in helping address the most challenging service needs, including behavioral planning and support and employment." Because MFP has data collection requirements, states can also provide specific information on the number of persons transitioned through the program into the community. According to the states' responses, since 2007, 247 individuals have been transitioned in Arkansas; 900 in California; 1,400 in Connecticut; 94 in Delaware; 178 in Hawaii; 783 in Illinois; 562 in Missouri; and more than 1,800 in Washington. Texas, where the MFP program originated as a state initiative, reported that, since the initial state program began in 2001, more than 35,000 individuals have been transitioned into community settings. West Virginia, which received a MFP grant in 2011, began its MFP program in fall 2012 and plans to transition 600 people into the community within the first five years.

Only two responding states, Wyoming and Arizona, do not use MFP. Arizona reported that the state "moved from institution early on, before the *Olmstead* mandate to deinstitutionalize," and has "a historically low rate of institutionalization." Arizona has used a §1115 waiver to provide Medicaid services since 1989, and the current structure of their program includes an "individualized assessment process … essentially guarantee[ing] that the 'money follows the person.'" The Arizona legislature also receives reports every year about "new individuals who move into a state operated ICF and why the placement was deemed most appropriate." Wyoming responded that they "analyzed the potential cost and benefits of [MFP] and decided that for the nursing home population, the program would not bring significant added value." The stated cited its Project Out program as a comparable alternative. Project Out functions as both a transition program, like MFP, and as a diversion program, and Wyoming reported that "[a]s time has gone by, the program has begun doing more diversions than transitions."

Section 1915(c) Waivers

Section §1915(c) waivers are one of the oldest federal programs focused on HCBS and have been a critical tool in the rebalancing that has occurred. Created by the Omnibus Budget Reconciliation Act (OBRA) of 1981,[72] these waivers offer important flexibility for overall costs and the types of populations that can be served, but can be both excessively relied upon and expensive to administer. Under a §1915(c) waiver, the state creates an alternative HCBS plan for Medicaid recipients meeting a NF or ICF level of care standard.[73] The plan can have different eligibility requirements and provide different benefits, but the average cost of the plan must be equal to or less than the average cost of care in an institution.[74] States can cap the number of people served by §1915(c) waivers and tailor individual waivers to a specific population.[75]

Twenty-eight responding states use §1915(c) waivers to provide HCBS.[76] The specificity of the populations served by §1915(c) waivers in each state demonstrates the extent to which waivers can be tailored. Each of these 28 states reports using a §1915(c) waiver to address the needs of disabled persons. Several other states also have specific waivers for persons with brain injuries and persons living with HIV. Massachusetts has a §1915(c) waiver for Children with Autism Spectrum Disorders, Kentucky has one for persons who are ventilator-dependent, and Michigan has one specifically for persons with substance use disorders. Of the responding states, Colorado offered the most waivers, with 12 different §1915(c) waivers, each of which targeted a different population group. California and

Connecticut have nine waivers; Iowa has seven; and Kentucky, Massachusetts, and Washington each have six, with Massachusetts planning to add more.

In general, states reported favorably on the flexibility of the waivers and the ability to implement a person-centered approach. For example, Iowa commented that the flexible supports offered by these waivers allow thousands of Iowans to remain in their homes and communities and access the services and supports they need. Wyoming noted that their waivers allow individuals with disabilities to have more control over their budgets, hire employees to provide services to them, and exercise more control over the quality and delivery of services. Oregon commented that it was "proud" to have been the first state in the nation to elect a 1915(c) waiver, which allowed the state to offer home and community-based alternatives to NFs.

Section 1115 Research and Demonstration Waivers

Section 1115 waivers were created as part of the original 1965 Medicaid enactment to allow states to experiment with the way that Medicaid services were provided.[77] The §1115 waivers were not designed to target the location of the services, but rather to promote the objectives of the Social Security Act broadly.[78] States can modify and redesign benefit packages, and federal matching funds can be used for things not otherwise allowable under Medicaid.[79] States can also modify the delivery system of Medicaid benefits, as was done with experiments into managed care in the 1990s, and can create cost control measures, since §1115 waivers must be budget-neutral.[80]

Section 1115 waivers are extremely flexible, and states can create very different programs under this waiver to serve their Medicaid populations. Eight of the responding states reported using §1115 waivers: Arizona, California, Delaware, Hawaii, Rhode Island, Tennessee, Texas, and Vermont. Three of these states stated that they use §1115 waivers to provide Medicaid services to all Medicaid-eligible individuals in their states: Arizona, Rhode Island, and Vermont. Arizona enacted its §1115 waiver in 1989 and incorporated HCBS into the benefits provided. The state reports providing "[HCBS] to everyone who qualified based on the individual's assessed need." Vermont has used a §1115 waiver to provide all Medicaid services since 2005, and Rhode Island created a similar state-wide managed care program through §1115 in 2010.

States seem to use §1115 waivers and §1915(c) waivers somewhat interchangeably, but a noticeable difference is that states find §1915(c) more useful for ID/DD populations. For example, Hawaii, Delaware, and Tennessee use §1115 waivers to provide statewide HCBS, but these states serve developmentally disabled individuals separately through §1915(c) waivers. Hawaii transitioned from all other §1915(c) waivers to a §1115 waiver in 2009, then viewing the §1115 waiver as an opportunity to promote "independence and choice among members." Since 2009, the §1115 waiver has met its initial goals, and Hawaii reports that it "has been successful in reducing institutionalization and is consistent with the requirements of both the ADA and *Olmstead*." Delaware also enacted a §1115 waiver, the Diamond State Health Plan, amid concerns about the state's institution-focused delivery system in 2011. The plan combined the rest of Delaware's §1915(c) waivers into the §1115 waiver, made services "no longer directed by a disability category," and enabled the state to "provide enhanced services geared towards the individual." Tennessee also uses a §1115 waiver, which it revised in 2008 to "fundamentally restructure long-term care" in the state.

New Mexico resubmitted a §1115 waiver request to "slow the rate of growth in the state's Medicaid program while avoiding program cuts" in August 2012. Minnesota has applied for a §1115 waiver "to continue to enhance community services for Minnesotans with disabilities" that would work in conjunction with Minnesota's five §1915(c) waivers.

Section 3: State Spending and Populations Served by HCBS

To understand states' current spending activities better, Chairman Harkin asked the states to report on current state spending on both institutional services and HCBS and to provide information on any expansion in the states' capacity to serve individuals in their own homes. In general, the responses demonstrate that state spending in different settings varies widely. Further, a majority of the responding states reported an increased capacity to serve individuals in the community, through either an overall increase in spending on HCBS since 2008 and/or an increase in the number of individuals served by HCBS during the same period. Only seven states reported on their expanded capacity to serve individuals in their own homes. Appendix 1 provides a summary of the information on spending and expansion capacity for all 31 states that provided substantive responses to the Chairman's request. Overall, the state responses showed that HCBS were more cost-effective in several states. The following section also identifies trends in spending and populations served by HCBS in the 11 follow-up states.

Cost-Effectiveness of HCBS

In general, the average cost to the state for individuals in ICFs was greater than the cost per person cost of providing HCBS. Although some programs, most notably §1915 waivers, require the average costs for service to be equal to or less than the average cost of care in an institution, the state responses show that HCBS are especially cost-effective. This data reinforces the conclusions of more than 38 studies published from 2005 to 2012, all of which found that providing HCBS is less costly than providing institution.[81]

Examples from the state responses include the following:

- In Alabama in 2012, the average cost per individual of the HIV Waiver was $6,370, the Elderly and Disabled Waiver was $11,041, and the Independent Living Waiver was $10,718. In contrast, the average cost per individual served in an Alabama NF was $36,593—a difference of at least $25,000.

- In Arizona in 2012, it cost $41,889 less per person to provide services at an ICF level of care through a §1115 waiver than to provide care in an ICF. Similarly, it cost $7,011 less per person to provide services at a nursing home level of care through a waiver program than to provide care in an NF. Since 1998, Arizona has saved more than $300 million by increasing the number of individuals served in HCBS.

- In Colorado in 2012, it cost about $20,000 less per person to provide HCBS than to provide care in an institution.

- In Connecticut in 2012, it cost about $100,000 less per person to provide an ICF level of care through the §1915(c) waiver program than to provide care in an ICF. Similarly, it cost $26,582 less per person to provide a nursing home level of care through the 1915(c) waiver program than to provide care in a NF.

- Delaware anticipates saving two million dollars during the first year of its new §1115 waiver program. Delaware noted that although "our investment in community based supports will not result in huge savings immediately…it will bend the cost curve over time while improving

consumer satisfaction, quality of life[,] and in meeting the spirit of the ADA Integration Mandate."

- In Iowa, it cost about $40,000 less per person to provide an ICF level of care though a §1915(c) waiver than to provide care in an ICF. It cost about $9,000 less to provide a nursing home level of care through the §1915(i) option, and about $6,000 less per person to provide care through the §1915 waiver, than to provide care in an NF.

- In Maryland in 2012, it cost about $14,000 less per person to provide a nursing home level of care though a §1915 waiver than to provide care in a NF. Similarly, it cost about $79,000 less per person to provide an ICF level of care through a §1915(c) waiver than to provide care in an ICF.

- In Minnesota, it cost about $11,000 less per person to provide a nursing home level of care through a §1915 waiver than to provide care in a NF. It cost about $3,000 less per person to provide an ICF level of care through the §1915(c) waiver than to provide care in an ICF. However, not all of the §1915(c) waivers in Minnesota were cost-effective: the Brain Injury Waiver, the Community Alternative Care Waiver, and Private Duty Nursing services were all more expensive than the cost of providing care in NFs.

- In New Mexico in 2012, it cost about $5,080 less per person to provide an ICF level of care through a §1915(c) waiver than to provide care in an ICF.

- In New York in 2011, it cost $176,000 less per person to provide an ICF level of care through a §1915(c) waiver than to provide care in an ICF. On the other hand, it cost more to provide the Personal Care Services Option, Consumer Directed Personal Assistance Program, and the §1915 waiver at the nursing home level of care than to provide care in institutional settings.

- In Texas in 2012, it cost about $10,102 less per person to provide a nursing home level of care through a §1915(c) waiver than to provide care in a NF. It cost $25,000 less per person to provide an ICF level of care through a §1915(c) waiver than to provide care in an ICF.

- In Vermont in 2012, it cost about $12,000 less per person to provide care through HCBS programs than to provide care in an NF.

- In Washington, "the state can serve an average of three individuals in community settings at costs similar to serving one individual in a nursing home." For example, it cost Washington about $50,402 less per person to provide an ICF level of care through a §1915(c) waiver than to provide care in an ICF. It costs the state about $12,000 less per person to provide a nursing home level of care through HCBS programs than to provide care in a NF.

Trends in Spending and Populations Served by HCBS in 11 States

The responding states provided information in varying formats, thus making it challenging to analyze trends among states. Consequently, to supplement the information received, Committee staff selected 11 states for additional follow-up discussions. The follow-up discussions included requests for additional information about spending associated with HCBS programs, as well as broad questions related to the cost-effectiveness of various HCBS programs. Although Committee staff does not have complete, uniform HCBS and institutional spending data for each state, the states that provided follow-up information are generally moving in the right direction by increasing the number of individuals

served by HCBS programs and decreasing the number of individuals receiving care in institutional settings. Six of the 11 states both increased the number of individuals served in HCBS and decreased the number of individuals in institutional settings at both the nursing home and ICF level of care,[82] and three states did so for at least one of the levels of care.[83]

However, the information provided by the follow-up states suggests that states are more focused on enrolling people that were already living in community settings into waivers and other HCBS programs than in transitioning individuals living in institutional settings back into the community, or are backfilling institutional beds rather than reallocating institutional funding to serve people in their own homes and communities. Across 10 of the 11 states, the increase in individuals served by HCBS was much larger than the decrease in individuals served in institutional settings.[84] For example, Colorado enrolled more than 5,300 additional people in HCBS at the nursing home level of care between 2008 and 2012, but the number of individuals in NFs dropped by only 84 people over the same time period. Similarly, Maryland increased the number of individuals served by HCBS programs at the nursing home level of care by 6,350 between 2008 and 2012, but it only decreased the number of people in nursing homes by 394 people.

Moreover, the financial information provided by the follow- up states confirmed publicly available data that show wide variations in spending on HCBS programs. Ten of the 11 states responded with sufficient information to determine the proportion of total state spending on services for individuals with disabilities spent on HCBS programs versus services in institutional settings. The proportion of funds spent on HCBS programs varied widely. Six states[85] spent more than half of their total funding on HCBS programs, led by Arizona and Minnesota which spent approximately 81 and 74 percent of their funding on HCBS respective. Of the other four,[86] Tennessee and Connecticut spent the lowest proportion on HCBS programs, at 39 and 37 percent respectively. The wide range of the proportion of state spending directed toward HCBS suggests that not all of the follow-up states are committing a basic floor of financial support to serve individuals with disabilities in home and community settings. This trend is reflected in a 2012 GAO report that shows an even wider variation in spending among the states that did not provide follow-up information for this report.[87] For example, the report finds that New Mexico spends about 80 percent of its total spending on HCBS, whereas Mississippi spends less than 20 percent on HCBS.[88]

States also provided information about the types of waivers and HCBS programs that they provide. Many of the states provide a comprehensive waiver or HCBS programs to individuals regardless of their type of disability, thus defining the population of individuals served by the level of their need or degree of functional impairment. In addition, most of the follow-up states provide waivers for specific age groups. Nine states provide a waiver or HCBS program specifically for elderly individuals.[89] Eight of the 11 states provide at least one waiver or HCBS program specifically for children,[90] and four states provide more than one.[91]

In addition to comprehensive waivers and HCBS programs, all of the follow-up states except Arizona provide programs targeted toward individuals with specific types of disabilities; the number of states varies widely based on the type of disability. Ten states provide at least one waiver or HCBS program specifically for individuals with ID/DD.[92] Eight of the 11 states provided more than one waiver for individuals with ID/DD.[93] In comparison, only four states provide a waiver or HCBS program specifically for individuals with mental illness.[94] (For people with mental illnesses, the Medicaid rehabilitation and case management options finance most of the HCBS provided.) Similarly, only four states provide a waiver or HCBS program specifically for individuals with physical disabilities.[95]

In the charts below, “N/R” indicates not reported and “N/A” indicates not applicable.

Arizona

Arizona spends the highest proportion of its total spending on HCBS of all of the follow-up states. The state has increased the number of individuals served through its single §1115 waiver by 30 percent since 2008, and it has decreased the number of individuals in NFs by almost 800 in the last four years. Arizona has also moved about 240 individuals out of ICFs. Arizona is unique among the follow-up states because it uses only one waiver to cover HCBS programs for individuals with disabilities. The §1115 waiver has operated since 1989 and uses a managed care model. The state has also recently announced its intention to utilize the CFC Option, such that the state stands to receive a six percentage point increase in their FMAP upon completion of the CMS approval process.

Arizona 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$1,759,845,062	$424,517,954	$2,184,363,017	81%

Individuals Served in Arizona by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**§1115 Waiver.** Provides long-term care services to Arizona residents who are aged, blind, physically disabled or developmentally disabled.	23,689	25,693	+1,995
	TOTAL HCBS	**23,689**	**25,693**	**+1,995**
	TOTAL NURSING FACILITIES	**7,679**	**6,897**	**-782**
ICF Level of Care	**§1115 Waiver**. Provides long-term care services to Arizona residents who are aged, blind, physically disabled or developmentally disabled.	20,486	24,858	+4,372
	TOTAL HCBS	**20,486**	**24,858**	**+4,372**
	TOTAL ICF/MR FACILITIES	**410**	**171**	**-239**

California

California failed to provide information from 2012 about the state's PCS option for individuals with physical disabilities or explain how the program will work in conjunction with CFC. The state also failed to provide sufficient data on the number of individuals served in NFs, ICFs, or in many of its HCBS options. As a result, Committee staff cannot determine California's total spending on HCBS, or the proportion of funds spent on HCBS and institutions, although a 2012 GAO report determined that the state spent about 55 percent of its total spending on HCBS in 2009.[96] The information that Committee staff did receive is summarized below.

Individuals Served in California by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Assisted Living Waiver.** §1915(c) waiver that provides services in residential care facilities or independent housing for individuals with disabilities age 21 and older and elderly adults.	875	1,420	+545
	Multipurpose Senior Services Program. §1915(c) waiver that provides care management and other supports for individuals age 65 or older.	13,600	12,081	-1,519
	In-Home Operations. §1915(c) waiver that serves people who require services by a licensed nurse or who require direct care services. It is no longer open to enrollment.	180	140	-40
	Nursing Facility/Acute Hospital. §1915(c) waiver that provides services for individuals age 21 and older with long-term medical conditions.	1,464	2,508	+1,044
	Pediatric Palliative Care. §1915(c) waiver that provides hospice-like care to children with life limiting conditions.	117	N/R	N/R
	San Francisco Community Living Support Benefit Waiver. §1915(c) waiver that provides care coordination, community living support benefits, behavior assessment and other services for individuals age 21 and older living in San Francisco.	N/R	N/R	N/R
	Money Follows the Person. Began operation in 2008.	2	492	+490
	§1915(k). This was approved in 2012.	N/A	N/A	N/A
	§1915(i). This was approved in 2013.	N/A	N/A	N/A
	Personal Care (In-Home Supportive Services program).	368,724	N/R	N/R
ICF Level of Care	**HIV/AIDS.** §1915(c) waiver that provides a continuum of care for persons with mid- to late-stage HIV/AIDS.	2,209	2,173	-36
	HCBS for Developmentally Disabled. §1915(c) waiver that provides services for developmentally disabled individuals through twenty-one regional centers.	72,678	82,856	+10,178
	Developmentally Disabled/Continuous Nursing Care. §1915(c) waiver that provides 24-hour continuous services to medically fragile individuals with DD.	NRP	53	N/R
	Money Follows the Person.	N/A	152	N/A
	§1915(i). This was approved in 2013.	N/R	40,000 (estimate)	N/R

Colorado

Colorado spends slightly more than half of its total budget on HCBS programs for individuals with disabilities. From 2008 and 2012, Colorado made some progress increasing the number of individuals

served in HCBS programs or through waivers, including increasing the number of people served by HCBS at the nursing home level of care by more than 5,000. The state increased the number of individuals served by the Community Mental Health Supports waiver by almost 450 during the same time period. Colorado has 15 different HCBS programs, including five for children with various types of disabilities and two specifically for individuals with ID. However, Colorado served 14,545 individuals in NFs in 2008 and 14,461 individuals in 2012 – a decrease of only 84 people. Further, Colorado actually increased the number of individuals served in ICF/MR facilities by 52 people.

Colorado 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$608,174,881	$559,003,335	$1,167,178,216	52%

Individuals Served in Colorado by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**HCBS for the Elderly, Blind, and People with Disabilities.** §1915(c) waiver for persons with disabilities who are 18 years old or older.	17,940	22,540	+4,600
	Community Mental Health Supports. §1915(c) waiver for individuals age 18 or older with a major mental illness.	2,399	2,847	+448
	Children's HCBS. §1915(c) waiver for children 17 and younger who are at risk of institutional placement but whose parents do not qualify for Medicaid.	1,205	1,379	+147
	Children with Life Limiting Illness. §1915(c) waiver for children age 19 and younger who are diagnosed with a life-limiting illness.	2	158	+156
	HCBS for People with Spinal Cord Injuries. §1915(c) waiver for individuals age 18 and older with a spinal cord injury.	0	16	+16
	Persons with Brain Injury. §1915(c) waiver that provides HCBS for people with brain injuries.	278	258	-20
	Persons Living with Aids. §1915(c) waiver for persons living with HIV/AIDS.	72	57	-15
	Money Follows the Person.	2	0	-2
	§1915(j). Program that provides self-directed personal assistance services.	40	33	-7
	TOTAL HCBS	**21,938**	**27,288**	**+5,350**
	TOTAL NURSING FACILITIES	**14,545**	**14,461**	**-84**
ICF Level of	**Children's Habilitation Residential Program.** §1915(c) waiver for children 21 and younger who are in foster care and have a DD.	157	124	-33

Individuals Served in Colorado by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Care	**HCBS Children with Autism.** §1915(c) waiver for children younger than six who are diagnosed with autism and are at risk of institutional placement.	73	101	+28
	Children's Extensive Support. §1915(c) waiver for children with serious disabilities.	435	401	-34
	HCBS Supported Living Services Program. §1915(c) waiver for people with DD who need low or moderate support.	3,095	3,309	+214
	People with Developmental Disabilities. §1915(c) waiver for adults with ID/DD.	4,283	4,393	110
	Money Follows the Person.	0	0	0
	TOTAL HCBS	**8,043**	**8,328**	**+285**
	TOTAL ICF/MR FACILITIES	**139**	**191**	**+52**

Connecticut

Connecticut spends only slightly more than a third of its total spending on HCBS. Since 2008, the state has reduced the number of people served in nursing and ICF/MR facilities. However, the number of individuals served in HCBS programs also decreased by approximately 209 individuals. Although the state served 450 people at the ICF level of care through the MFP program in 2012, the number of individuals served in ICF facilities has decreased by only 150 people since 2008. Connecticut has eight HCBS programs, including two waivers specifically for people with ID/DD and a new waiver for individuals with mental illness.

Connecticut 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$891,055,356	1,506,069,985	$2,397,125,341	37%

Individuals Served in Connecticut by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Connecticut Home Care Program for Elders**. §1915(c) waiver for individuals age 65 or older. Services provided include care management, day health care, companion services, and other supports.	11,757	10,474	-1,283

Individuals Served in Connecticut by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
	Mental Health Waiver. §1915(c) waiver for adults with serious mental illness. Services provided include: rehabilitative and support services, residential based services, and other ancillary services. Started in 2010.	N/A	89	89
	Acquired Brain Injury Waiver. §1915(c) waiver for adults between 18 and 64. Services provided include skills training, homemaker services, transitional living services, and other supports.	364	393	+29
	Personal Care Assistance Waiver. §1915(c) waiver for adults between 18 and 64 with a physical disability that require help with at least two activities of daily living.	778	819	+41
	TOTAL HCBS	**12,899**	**11,775**	**-1,124**
	TOTAL NURSING FACILITIES.	**17,466**	**16,748**	**-718**
ICF Level of Care	**Katie Beckett Waiver.** §1915(c) waiver for severely disabled individuals – primarily children.	185	188	+3
	Individual and Family Support Waiver. §1915(c) waiver that provides personal assistance, supported living, and respite for individuals with ID/DD.	3,434	3,746	+312
	Comprehensive Waiver. §1915(c) waiver for individuals with ID/DD living in Community Living Arrangements, Community Training Homes, or Assisted Living facilities.	4,471	4,621	+150
	Money Follows the Person.	N/A	450	N/A
	TOTAL HCBS	**8,090**	**9,005**	**+915**
	TOTAL ICF/MR FACILITIES	**1,129**	**1,004**	**-125**

Iowa

Iowa spends less than half of its total spending on HCBS. The state has 12 different HCBS programs, and it has made some progress both increasing the number of individuals served by HCBS and decreasing the number of individuals served in institutions. However, the state only decreased the number of individuals in ICF/MR facilities by 131 people between 2008 and 2012. In June 2013, CMS approved Iowa's application for a BIP grant, so that the state will receive an increase in its FMAP by two percent, for a total of approximately 61 million dollars.

Iowa 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$545,863,855	$818,745,274	$1,364,609,129	40%

Individuals Served in Iowa by Program, Waiver, or Location				
Program, Waiver, or Location Description		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Elderly Waiver.** §1915(c) waiver that provides adult day care, nursing care, senior companions, home health aides, and other services.	12,166	11,866	-300
	Children's Mental Health Waiver. §1915(c) waiver for children age 18 and younger with serious emotional disturbances. It provides environmental modifications, family and community support services, in home family therapy, and other supports.	663	979	+316
	Money Follows the Person.	N/A	0	0
	Balancing Incentives Payment. Iowa received approval for this grant in 2012.	N/A	N/A	N/A
	§1915(i) Waiver. In 2007, Iowa became the first state to receive approval for this option.	3,127	5,362	+2,235
	TOTAL HCBS	**15,956**	**18,207**	**+2,251**
	TOTAL NURSING FACILITIES	**19,005**	**17,772**	**-1,233**
ICF Level of Care	**Intellectual Disabilities Waiver.** §1915(c) waiver for individuals with ID that provides adult day care, consumer directed attendant care, day habilitation, and additional services.	10,741	11,875	+1,134
	Ill and Handicapped Waiver. §1915(c) waiver for blind or disabled individuals that provides adult day care, consumer directed attendant care, counseling services, and other services.	2,754	2,815	+61
	Persons with Physical Disabilities Waiver. §1915(c) waiver for individuals age 18 through 64 that provides consumer directed attendant care, home and vehicle modification, specialized medical equipment, and other services.	835	1,010	+175
	HIV/AIDS Waiver. §1915(c) waiver for individuals diagnosed with HIV/AIDS that provides adult day care, consumer directed attendant care, counseling services, and other services.	54	42	-12
	Money Follows the Person.	N/A	119	+119
	Balancing Incentives Payment. Iowa received approval for this program in 2012.	N/A	N/A	N/A
	§1915(i) Waiver. In 2007, Iowa became the first state to receive approval for this option.	0	0	0
	TOTAL HCBS	**14,384**	**15,861**	**+1,477**
	TOTAL ICF/MR FACILITIES	**2,294**	**2,163**	**-131**

Maryland

Maryland spends less than half of its total funding on providing HCBS for individuals but has made progress both increasing the number of individuals served by HCBS programs and decreasing the number of individuals served in ICF/MR facilities. Since 2009, Maryland has closed two ICF/MR facilities and reduced the number of people served in an ICF/MR facility by 170 individuals. Maryland has 10 different HCBS programs, including two specifically for children and two for individuals with ID/DD. Maryland is planning to begin implementation of the CFC Option in 2014.

Maryland 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$980,450,402	$1,184,410,834	$2,164,861,236	45%

Individuals Served in Maryland by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Living at Home Waiver.** §1915(c) waiver for individuals age 18 and 64 with physical disabilities. The waiver provides nursing supervision, assistive technology, attendant care, and other services.	564	754	+190
	Model Waiver for Fragile Children. §1915(c) waiver for chronically ill or severely impaired children younger than 22. Services provided include case management, nursing and home health aides, medical equipment and supplies, and other services.	208	197	-11
	Medical Day Care Services. §1915(c) waiver for functionally impaired individuals age 16 and older. The waiver provides medical care in community-based settings.	N/A	4,671	N/A
	Older Adults. §1915(c) waiver for adults age 50 and over. Services provided include personal care, respite care, assisted living services, and other services.	3,426	3,927	+501
	Traumatic Brain Injury. §1915(c) waiver for individuals suffering traumatic brain injury after the age of 17. Services provided include residential and day habilitation and employment support.	30	48	+18
	Money Follows the Person.	162	320	+158
	Personal Care. State plan option that serves people who need assistance with at least one activity of daily living.	4,324	5,147	+823
	TOTAL HCBS	**8,714**	**15,064**	**+6,350**
	TOTAL NURSING FACILITIES	**22,727**	**22,333**	**-394**

Individuals Served in Maryland by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
ICF Level of Care	**Community Pathways.** §1915(c) waiver for individuals with DD. It provides residential, day and supported employment services, family and individual support services, and other services.	11,203	12,746	+1,543
	New Directions Independence Plus. §1915(c) waiver for individuals with DD. It allows individuals to direct their own services with the assistance of a support broker.	96	213	+117
	Waivers for Children With Autism Spectrum Disorder. §1915(c) waiver for children age 1 to 21 who receive at least 12 hours of special education services per week. Services provided include therapeutic integration, respite care, residential habilitation, and other services.	853	888	+35
	TOTAL HCBS	**12,152**	**13,847**	**+1,695**
	TOTAL ICF/MR FACILITIES	**310**	**140**	**-170**

Minnesota

Minnesota spends three-fourths of its total spending on individuals with disabilities providing HCBS. Since 2008, Minnesota has increased the number of individuals served by HCBS by nearly 20,000 and decreased the number of individuals in institutional facilities by more than 2,500. As a result, Minnesota has even been able to close some state ICF/MR facilities. Minnesota operates 14 HCBS programs, including two for elderly individuals and two for individuals with ID/DD.

Minnesota 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$2,689,445,767	$914,734,132	$3,604,179,899	75%

Individuals Served in Minnesota by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Brain Injury Waiver.** §1915(c) waiver that provides 24-hour customized living, adult companions, adult day care, and other services to individuals younger than 65 with brain injuries.	1,315	1,341	+26
	Community Alternatives for Disabled Individuals. §1915(c) waiver that provides 24-hour customized living, adult companions, day care, and other services to individuals younger than 65.	11,763	16,463	+4,700

Individuals Served in Minnesota by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2012 Individuals Served**	**Net Change**
	Community Alternative Care. §1915(c) waiver that provides case management, consumer directed community supports, extended home care, and other services for individuals younger than 65 who are chronically ill.	279	331	+52
	Elderly Waiver. §1915(c) waiver that provides adult day care, community residential services, skilled nursing, and other services to individuals who are 65 and older.	18,366	24,910	+6,544
	Alternative Care. Waiver for individuals who are age 65 or older and require a nursing home level of care but who are not eligible for Medical Assistance	3,371	2,983	-388
	Money Follows the Person. Enrollment began in 2013.	N/A	N/A	N/A
	Personal Care Services. Provides in-home services to persons with physical, emotional, or mental disabilities, a chronic illness or an injury.	16,746	23,679	+6,933
	Private Duty Nursing. Provides individual, continuous services to individuals with illness, injury, or physical or mental condition.	477	612	+135
	Home Health option.	5,116	5,015	-101
	TOTAL HCBS	**57,433**	**75,334**	**+17,901**
	TOTAL NURSING FACILITIES	**19,468**	**17,053**	**-2,415**
ICF Level of Care	**Developmental Disability.** §1915(c) waiver that provides adult day care, day training and habilitation services, consumer-directed community supports, and other services to individuals with DD.	13,971	15,445	+1,474
	Money Follows the Person. Enrollment began in 2013.	N/A	N/A	N/A
	Consumer Support Grant. State-funded cash grants that can be used to pay both professional and non-professional caregivers such as a family member.	1,040	1,541	+501
	Family Support Grant. Provides cash grants to families of children younger than 21 with disabilities. The funds can be used for a variety of family-centered services.	1,628	1,628	0
	Semi-Independent Living Services. Provides training and assistance to individuals age 18 or older who have DD.	1,552	1,552	0
	TOTAL HCBS	**18,191**	**20,166**	**+1,975**
	TOTAL ICF/MR FACILITIES	**1,850**	**1,720**	**-130**

New York

New York 2011 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
10,514,912,351	10,025,954,102	20,540,866,453	51%

Individuals Served in New York by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Long Term Home Health Care Program.** §1915(c) waiver for individuals with disabilities whose care costs are less than the cost of providing care in a nursing home.	25,527	28,117	+2,590
	Nursing Home Transition and Diversion Medicaid Waiver. §1915(c) waiver that provides skills training, assistive technology, and other services to individuals with disabilities who are transitioning from NFs or who are at risk of entering NFs.	30	1,566	+1,536
	Traumatic Brain Injury. §1915(c) waiver that provides service coordination, assistive technology, independent living skills training, and other supports for adults age 18 and older.	2,891	3,110	+219
	Care at Home I/II. §1915(c) waiver that provides case management, pain management, home modifications, and other services to children with physical disabilities ages 0-17.	633	954	+321
	CAH III. §1915(c) waiver that provides case management and respite care for children with developmental disabilities ages 0-17.	212	187	-25
	CAH IV. See CAHIII	223	199	-24
	CAH VI. See CAHIII	207	203	-4
	Bridges to Health for Children who are Medically Fragile. §1915(c) waiver that provides wrap-around care to children in foster care with significant health care needs.	13	138	+125
	Bridges to Health for Children w/SED. §1915(c) waiver that provides wrap-around care to children in foster care with mental illness.	278	3,720	+3,442
	Bridges to Health for Children w/DD. §1915(c) waiver that provides wrap-around care to children in foster care with developmental disabilities.	53	456	+403
	OMH (all) SED. §1915(c) waiver that provides case management, skill building, crisis response, and other services for children with mental illness ages 5-21.	1,975	2,637	+662

Individuals Served in New York by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
	OMRDD (OPWDD) Comprehensive. §1915(c) waiver that provides habilitation services, adaptive technology, respite care, and other services to both children and adults with developmental disabilities.	67,583	77,815	+10,232
	Money Follows the Person.	N/A	240	N/A
	Personal Care. Provides housekeeping, meal preparation, bathing, and other services to people with disabilities.	69,073	57,930	-11,143
	Consumer Directed Personal Assistance Program. Provides personal care aides, home health aides, and nurses to people with chronic illness or physical disabilities.	9,112	10,706	+1,594
	TOTAL HCBS	**177,810**	**187,978**	**+10,168**
	TOTAL NURSING FACILITIES	**132,833**	**129,660**	**-3,173**
ICF Level of Care	**Long Term Home Health Care Program**. §1915(c) waiver for individuals with disabilities whose care costs are less than the cost of providing care in a nursing home.	N/R	N/R	N/R
	Personal Care. Provides housekeeping, meal preparation, bathing, and other services to people with disabilities.	N/R	N/R	N/R
	Money Follows the Person.	N/R	N/R	N/R
	TOTAL HCBS	**N/A**	**N/A**	**N/A**
	TOTAL ICF/MR FACILITIES	**8,260**	**7,841**	**-419**

About half of New York's total spending on individuals with disabilities is spent on HCBS. Since 2008, the state has increased the number of individuals served through HCBS programs at the nursing home level of care by more than 10,000 and decreased the number of people in nursing and ICF facilities by more than 3,500. However, while New York has fifteen different HCBS programs at the nursing home level of care that cover varied types of disabilities and age groups, the state serves no people through HCBS at the ICF level of care. New York is also planning to implement the Community First Choice Option starting in October 2013.

Tennessee

Less than half of Tennessee's total spending on individuals with disabilities is spent on HCBS programs. The state has made some progress in increasing the number of individuals served by HCBS programs and decreasing the number of individuals served in institutions. Although Tennessee increased the number of individuals receiving HCBS services at the ICF/MR level of care by only 26 people, it decreased the number of individuals served in NFs by more than 2,000 people. In addition to TennCare and the §1915(c) waivers, Tennessee began implementing MFP in 2011.

Tennessee 2012 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$715,461,300	$1,122,461,154	$1,837,922,454	39%

Individuals Served in Tennessee by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
Nursing Home /At Risk of Nursing Home Level of Care	**§1915(c) Waivers.**	2,331	N/A	N/A
	TennCare CHOICES. §1115 waiver for elderly adults or physically disabled adults age 21 and older. The waiver, launched in 2010, provides assistance with performing everyday activities in the home as well as nursing home services.	N/A	9,991	N/A
	Other HCBS Programs (including MFP starting in 2011).	3,626	4,678	+1,052
	TOTAL HCBS	**5,957**	**14,669**	**+8,712**
	TOTAL NURSING FACILITIES	**23,089**	**21,203**	**-1,886**
ICF Level of Care	**§1915(c) Waivers.** These include the Self-Determination Waiver, the Statewide Waiver, and the Arlington Waiver, all of which provide services for individuals with ID.	7,822	7,848	+26
	TOTAL HCBS	**7,822**	**7,848**	**+26**
	TOTAL ICF/MR FACILITIES	**1,215**	**1,072**	**-143**

Texas

Slightly more than half of Texas' total spending on individuals with disabilities is spent on HCBS. Since 2008, the state has increased the number of individuals served by HCBS and decreased the number of individuals in ICD/MR facilities. However, the number of individuals in NFs increased by 550 people between 2008 and 2011. Texas provides 25 different HCBS programs, including three programs specifically for individuals with ID/DD. Additionally, Texas received CMS approval for a BIP grant in 2012.

Texas 2011 HCBS and Institutional Expenditures			
HCBS Spending	**Institutional Spending**	**Total Spending**	**Percentage HCBS**
$3,819,512,347	$3,306,107,928	$7,125,620,275	54%

Individuals Served in Texas by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
Nursing Home Level of Care	**Community Based Alternatives.** §1915(c) waiver that provides HCBS services in the home, adult foster care, assisted living, or residential care facilities.	29,158	16,805	-12,353
	Medically Dependent Children Program. §1915(c) waiver that provides adaptive aids, adjunct support services, minor home modifications, and other services to disabled, dependent children and their families.	3,050	5,524	+2,474
	STAR+PLUS CBA. §1915(c) waiver that provides adaptive aids, medical supplies, adult foster care and other services to adults with a disability. The services are provided through managed care.	8,207	29,037	+20,830
	Primary Home Care. Provides medically related personal care services to functionally limited adults.	51,569	30,125	-21,444
	Community Attendant Services. Provides medically related personal care services to functionally limited adults and children.	42,149	46,588	+4,439
	Day Activity and Health Services. Provides supports for the physical, mental, medical, and social needs of disabled individuals.	16,605	9,775	-6,830
	STAR+PLUS §1915(b)/(c) / §1115 Waiver. Provides adaptive aids, medical supplies, adult foster care and other services to adults with a disability. The services are provided through managed care.	27,013	67,781	+40,768
	Program of All-inclusive Care for the Elderly (PACE). Provides a wide array of services to the elderly for a monthly fee less than the cost of nursing facility care.	904	1,016	+112
	TOTAL HCBS	**178,655**	**206,651**	**+27,996**
	TOTAL NURSING FACILITIES	**62,592**	**63,142**	**+550**
ICF Level of Care	**Community Living Assistance & Support Services (CLASS).** §1915(c) waiver that provides HCBS for individuals with ID.	3,833	4,801	+968
	Deaf, Blind w/Multiple Disabilities. §1915(c) waiver that provides adaptive aids, nursing services, transition assistance, and other services for individuals who are deaf or blind and have another disability.	147	149	+2
	Home and Community-based Services. §1915(c) waiver that provides day habilitation, nursing, residential assistance, and other services to individuals with ID.	13,386	19,863	+6,477

Individuals Served in Texas by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
	Texas Home Living Program. §1915(c) waiver that provides behavioral support, day habilitation, nursing, and other services to individuals with ID.	1,243	3,934	+2,691
	Intellectual Disability Community Services. Provides in-home attendant services to adults and children who are functionally limited.	12,860	4,481	-8,379
	TOTAL HCBS	**31,469**	**33,228**	**+1,759**
	TOTAL ICF/IID FACILITIES	**11,177**	**9,499**	**-1,678**
Inpatient Psychiatric Level of Care	**Youth Empowerment Services 1915(c) waiver.** Provides community living supports, family supports, professional services, and other supports to children with serious emotional disturbances. CMS approved the waiver in 2009.	N/A	89	N/A
	TOTAL INPATIENT PSYCHIATRIC	**N/A**	**89**	**N/A**
Other	**Money Follows the Person.** Data included in other line items.	N/A	N/A	N/A
	Balancing Incentive Program. CMS approved BIP in 2012.	N/A	N/A	N/A
	Day Activity and Health Services. Provides nursing, physical rehabilitation, personal care, and other services for individuals with functional limitations age 18 or older.	1,801	2,486	+685
	In-Home and Family Services. Provides direct grants to individuals with physical disabilities so that they can purchase their own supportive services.	4,562	5,999	+1,437
	Adult Foster Care. Provides alternative living arrangements for individuals with physical, mental, or emotional disabilities.	102	55	-47
	Client Managed Personal Attendant Services. Provides personal assistance services to individuals with physical disabilities.	470	394	-76
	Family Care. Provides attendant services for adults with functional disabilities.	6,252	5,454	-798
	Emergency Response Services. Provides 24 hour emergency response for socially isolated, functionally impaired individuals.	17,973	14,439	-3,534
	Home Delivered Meals. Provides meals for people 18 years of age or older who are functionally limited.	16,850	15,185	-1,665
	Residential Care. Provides 24 hour assisted living for individuals with disabilities.	570	462	-108

Individuals Served in Texas by Program, Waiver, or Location				
Program, Waiver, or Location		2008 Individuals Served	2011 Individuals Served	Net Change
	Special Services for Persons with Disabilities. Provides counseling, personal care, skill development, and other services for persons with disabilities age 18 or older.	121	86	-35
	TOTAL OTHER	48,701	44,560	-4,141

Washington

Washington spends more than half of its total spending on individuals with disabilities on HCBS programs. Since 2008, Washington has made progress both increasing the number of individuals served in HCBS programs and decreasing the number of individuals served in institutional settings. Washington has made substantially more progress at the nursing home level of care than the ICF/MR level of care, although the state was able to close an ICF/ID facility in 2012. Washington provides 13 different HCBS options.

Washington 2011 HCBS and Institutional Expenditures			
HCBS Spending	Institutional Spending	Total Spending	Percentage HCBS
$1,433,663,000	$705,690,000	$2,139,353,000	67%

Individuals Served in Washington by Program, Waiver, or Location				
Program, Waiver, or Location		2008 Individuals Served	2011 Individuals Served	Net Change
Nursing Home Level of Care	**Medically Needy Residential.** §1915(c) waiver that provides boarding home care, adult family home care, skilled nursing, and other services to elderly individuals and individuals with physical disabilities. This waiver has been discontinued.	N/A	N/A	N/A
	Medically Needy In-Home. §1915(c) waiver that provides home delivered meals, home health aides, skilled nursing, and other services to elderly individuals and individuals with physical disabilities.	140	96	-44
	New Freedom. §1915(c) waiver that provides self-directed services for elderly adults and adults with disabilities.	98	761	+663
	Community Options Program Entry System (COPES). §1915(c) waiver that provides assisted living, adult family home care, and other services to elderly adults and individuals with physical disabilities.	31,008	35,120	+4,112
	Money Follows the Person. Implementation began in 2008.	N/A	1,294	N/A
	State Plan Medicaid Personal Care. Provides assistance with personal care tasks for functionally impaired adults.	17,913	20,390	+2,477

Individuals Served in Washington by Program, Waiver, or Location				
Program, Waiver, or Location		**2008 Individuals Served**	**2011 Individuals Served**	**Net Change**
	TOTAL HCBS	**49,159**	**57,661**	**+8,502**
	TOTAL NURSING FACILITIES	**19,462**	**18,776**	**-686**
ICF Level of Care	**Children's Intensive In-Home Behavioral Support.** §1915(c) waiver provides private duty nursing for children with challenging behaviors. Implementation began in 2009.	N/A	69	N/A
	Community Protection. §1915(c) waiver that provides skilled nursing, residential habilitation, behavior management, and other services to individuals with a DD.	460	475	+15
	Basic Plus Waiver. §1915(c) waiver that provides the same services as the basic waiver as well as skilled nursing, adult foster care, and adult residential care.	2,123	2,635	+512
	Basic Waiver §1915(c) waiver that provides individuals with ID personal care, respite, medical equipment, and other services.	2,845	4,230	+1,385
	CORE Waiver. §1915(c) waiver that provides residential habilitation, skilled nursing, therapy, and other services to individuals who have ID.	4,082	4,257	+175
	Money Follows the Person. Implementation began in 2008.	N/A	48	N/A
	State Plan Medicaid Personal Care. Provides assistance with personal care tasks for functionally impaired adults.	7,754	7,432	-322
	TOTAL HCBS	**17,264**	**19,146**	**+1,882**
	TOTAL ICF/MR FACILITIES	**1,268**	**1,151**	**-117**

Section 4: Progress in Moving Individuals with Disabilities into Homes and the Community

To gain a more complete understanding of the states' progress in providing services to individuals with disabilities, Committee staff assessed current information on the demographic composition of individuals in nursing homes. In addition, Chairman Harkin requested that the states provide information on how states have increased access to HCBS in the years since *Olmstead*. Specifically, the Chairman asked states to include the number of individuals with disabilities who have transitioned from nursing homes, ICFs for individuals, long-term care units of psychiatric hospitals, and adult care facilities into living in their own homes, including through a supportive housing program.

Nursing Home Populations

Given the ADA's mandate to serve individuals with disabilities in the most integrated environment, states should be providing these individuals with the supports that they need to live in the community. Nursing homes continue to be widely used, however, to serve individuals with disabilities. A popular assumption is that nursing facilities primarily serve older adults. Yet, as shown in in the table below, 14 years after the *Olmstead* decision, there are still more than 200,000 individuals younger than 65 residing in nursing homes. Moreover, studies show that the proportion of nursing home residents younger than 65 is increasing over time. From 2000 to 2007, nursing home use increased among adults age 31 to 65 in 48 states. Nationwide, the proportion of nursing home residents younger than 65 increased from 12.9 percent in 2005 to 14.2 percent in 2009.[97] Similarly, between 2008 and 2012, the working age adults in nursing homes increased by over 30,000 people, from 193,533 in 2008 to 224,434 in 2012—or a quarter of a million people. According to current CMS data, people under 65 now make up almost 16 percent of the current nursing home population. Although the number of nursing home residents under 65 in nursing homes is growing, the percent of all adults age 30 and younger living in nursing homes is still less than one percent.[98] The following chart compares states' nursing home populations under age 65 in 2008 and 2012, as well as a ranking of the states by the overall percentage of the states' under-65 population residing in nursing homes in 2012. The first column lists the states in decreasing order according to the percentage of their total population under age 65 that was institutionalized in nursing homes in 2012.

Comparison of 2008 and 2012 Nursing Home Population under 65					
State	**2008 Nursing Home Population < 65**	**2012 Nursing Home Population <65**	**Percent Change**	**2008 Ranking of Populations < 65 in Nursing Homes.**	**2012 Ranking of Populations <65 in Nursing Homes.**
Illinois	16,949	17,484	3.16	1	1
Ohio	12,574	14,882	18.36	2	2
Missouri	5,939	7,103	19.60	4	3
Louisiana	4,781	5,372	12.36	3	4
Mississippi	2,422	2,851	17.71	8	5
Connecticut	3,051	3,270	7.18	5	6
South Dakota	529	740	39.89	19	7
Oklahoma	3,122	3,319	6.31	6	8
Arkansas	2,406	2,568	6.73	7	9
New York	15,049	17,048	13.28	9	10
New Jersey	6,349	7,603	19.75	13	11
Kansas	2,008	2,426	20.82	12	12
Indiana	4,822	5,450	13.02	11	13
Nebraska	1,391	1,513	8.77	10	14
Massachusetts	4,511	5,372	19.09	14	15
Alabama	3,213	3,803	18.36	17	16
Maryland	3,778	4,567	20.88	18	17
Iowa	2,064	2,299	11.39	15	18
Pennsylvania	7,556	9,523	26.03	23	19
West Virginia	1,157	1,384	19.62	22	20
Tennessee	4,277	4,630	8.25	16	21
North Dakota	431	488	13.23	21	22
Kentucky	2,792	3,128	12.03	20	23
Delaware	503	629	25.05	25	24
Rhode Island	570	735	28.95	27	25
Texas	13,267	16,761	26.34	28	26
Maine	509	852	67.39	39	27
Georgia	5,284	5,921	12.06	26	28

Comparison of 2008 and 2012 Nursing Home Population under 65					
State	**2008 Nursing Home Population < 65**	**2012 Nursing Home Population <65**	**Percent Change**	**2008 Ranking of Populations < 65 in Nursing Homes.**	**2012 Ranking of Populations <65 in Nursing Homes.**
Montana	578	595	2.94	24	29
California	19,490	22,360	14.73	28	30
Florida	9,206	11,213	21.80	32	31
North Carolina	4,717	5,454	15.62	30	32
Virginia	3,665	4,462	21.75	34	33
Minnesota	2,613	2,948	12.82	31	34
Michigan	4,505	5,349	18.73	35	35
Utah	1,162	1,495	28.66	37	35
Colorado	2,192	2,544	16.06	36	37
Wisconsin	2,703	2,788	3.14	33	38
New Mexico	759	992	30.70	41	39
New Hampshire	487	611	25.46	40	40
Washington	2,811	2,995	6.55	38	41
South Carolina	1,648	2,040	23.79	44	42
Idaho	575	689	19.83	42	43
Vermont	*211	269	*27.49	45	44
Nevada	842	1,144	35.87	48	45
Arizona	2,141	2,637	23.17	46	46
Wyoming	*206	225	*9.22	43	47
Oregon	1,219	1,385	13.62	47	48
Hawaii	351	390	11.11	49	49
Alaska	*148	128	*13.51	50	49
TOTAL	***193,533**	**224,434**	***15.97%**		

***Includes the under-30 nursing home population.

Transitions into the Home and Community

In response to the Chairman's request, most states reported general information on transitions, such as transitions to the "community," "integrated settings" or "HCBS settings." However, the states did not provide any clarification as to what these terms encompass. Only 14 states provided specific

information on transitions into homes: Alabama, Alaska, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Massachusetts, Minnesota, Missouri, Texas, and Washington. California reported the highest number of transitions from NFs into homes or independent home settings.

Part of the problem may be a continued lack of clarity on the definition of "home and community-based setting." For example, Hawaii and Minnesota reported on transitions into homes, but defined a "home" as including being homeless, residing in a car, or living in a DD home. Other states consider alternative or assisted living facilities to be community settings, although most disability advocates believe that these settings do not fulfill the integration mandate or provide the cost savings advantage of other HCBS options. In fact, state licensing requirements and definitions of assisted living vary widely. Such facilities can range in size from a small residential house to a very large facility that provides services to hundreds of residents, with a level of care that falls anywhere between an independent living community and a skilled NF. Definitions of group homes are also problematic. For example, a group home for the mentally ill in Minnesota serves five or more clients, whereas mental health group homes in Connecticut serve 16 or fewer people. Under Texas law, there are a couple of dozen types of homes, houses, centers, and other facilities that qualify as group homes. [99]

CMS issued a new proposed definition of HCBS last May as part of its final rule implementing the CFC Option, along with a call for public comments. The ACA itself specifies that HCBS settings do not include an NF, institution for mental diseases, or ICF/MR. CMS found that the existing definition created confusion. Thus, its current proposal focuses on both the types of settings as well as those qualities considered to be essential in determining whether a setting is community-based, such as access to the greater community, opportunities for employment, protection of privacy and freedom from restraint, and independence in all life choices.[100] Some states have expressed concern over this definition, claiming that it could unintentionally restrict individuals' choices by only allowing a very limited group of places to be deemed HCBS settings.

Highlights from the state responses follow:

Alabama

Alabama reported closing the last state-run ICF for individuals with ID in 2012. The state does not currently collect data on transitions from nursing homes or board and care homes, but it reported the following information on transitions from other facilities:

Transitions in Alabama					
Type of Transition	**Number of Individuals Transitioned by Year**				
	2008	**2009**	**2010**	**2011**	**2012**
From nursing facilities	Data not collected	Data not collected	Data not collected	Data not collected	Data not collected
From ICF/ID to own home	2	3	3	1 (156 to community group homes)	Facility closed
From long-term care units— psychiatric hospitals— to own home	20	18	25	5	1

Transitions in Alabama					
Type of Transition	**Number of Individuals Transitioned by Year**				
	2008	**2009**	**2010**	**2011**	**2012**
From psychiatric group homes to independent living (homes, apartments, supportive housing)	439	435	430	403	343

Alaska

Alaska generally reported downsizing its institutional settings in favor of transitioning individuals to HCBS. For example, the state's only public inpatient psychiatric hospital, originally equipped to house 242 patients, downsized to a bed capacity of 80. Alaska also reported the following transitions:

Transitions in Alaska					
Type of Transition	**Number of Individuals Transitioned by Year**				
	2008	**2009**	**2010**	**2011**	**2012**
From skilled nursing facility to home	79	101	104	92	Not reported
From ICF/ID (out-of-state) to unspecified location	1	2	1	1	1
From inpatient psychiatric stay greater than 60 days to community living	No data	21	32	36	15

Arizona

Arizona reported that less than one percent of the more than 30,000 individuals served by its Division of Developmental Disabilities live an institutional setting. According to the state, the only persons that remain in an institutional setting are those who choose not to leave or those unable to be cared for in a non-institutional setting. As a result, the state does not track the number of individuals who move out of institutions. However, the state does track the number of new individuals who move into a state-operated ICF. Currently, approximately 185 people live in an ICF and 50 people in a skilled NF. As of March 2012, six people live in assisted living facilities. Arizona also collects data on the number of individuals served by the public behavioral health system who have transitioned from facility settings, including ICFs, nursing homes, psychiatric hospitals, or residential care facilities, to living in their own homes or with friends and family, as shown in the table below. The state also noted that the vast number of individuals receiving services (83 percent) live independently at admission into treatment.

Transitions in Arizona					
Transition From	**Number of Individuals Transitioned by Year**				
	2008	**2009**	**2010**	**2011**	**2012**
A facility setting at admission to independent living arrangements	1,270 (33.7% of population in facilities)	1,478 (32.7 % of population in facilities)	1,306 (33.8% of population in facilities)	1,126 (28.7% of population in facilities)	Not reported

Arkansas

Arkansas reported using its Alternative Community Service section §1915(c) waiver to transition individuals into more integrated settings:

Transitions in Arkansas					
Transition From	**Number of Individuals Transitioned to More Integrated Settings by Year**				
	2008	**2009**	**2010**	**2011**	**2012 (through September)**
State hospitals	3	7	10	15	11
Human development center	15	17	14	31	16
ICF	15	27	15	31	14
Nursing facility	10	4	4	4	2

California

California reported transitioning an average of 151,804 individuals from skilled NFs into their own homes or independent home settings (including apartments, duplexes, and single room occupancies) from 2008 through 2011. California also reported the number of transitions for each year: 139,138 in 2008; 146,440 in 2009; 157,243 in 2010; and 164,394 in 2011.

Colorado

Colorado reported the total number of individuals who have transitioned from a nursing home, ICF/ID, or psychiatric facility, to a HCBS program funded through Medicaid:

Transitions in Colorado					
Transition From	**Number of Individuals Transitioned to HCBS Setting by Year**				
	2007 to 2008	**2008 to 2009**	**2009 to 2010**	**2010 to 2011**	**2011 through August 2012**
Nursing home	124	167	151	165	102
ICF/ID	4	8	29	7	5

Transitions in Colorado					
Transition From	**Number of Individuals Transitioned to HCBS Setting by Year**				
	2007 to 2008	**2008 to 2009**	**2009 to 2010**	**2010 to 2011**	**2011 through August 2012**
Long-term care psychiatric hospital	174	180	150	129	119

Colorado also reported a breakdown of the number of transitions into specific types of HCBS settings:

Transitions in Colorado					
Type of HCBS setting	**Number of Individuals Transitioned by Year**				
	2007 to 2008	**2008 to 2009**	**2009 to 2010**	**2010 to 2011**	**2011 through August 2012**
Alternative Care facility	62	75	70	78	38
Group home	8	16	32	9	5
Own home	58	84	78	85	64

In addition, Colorado noted that it uses subsidized housing vouchers for people with disabilities and the elderly.

Connecticut

Connecticut reported transitions into the home under various Medicaid waivers and state programs. Specifically, Connecticut reported transitions under its (1) Acquired Brain Injury Waiver, which addresses the needs of persons disabled by acquired brain injuries who currently receive, or would otherwise require, services in an institutional setting; (2) Mental Illness (MI) Waiver, which services children with severe emotional disturbance; (3) the Department of Developmental Services (DDS) Waiver, which provides a variety of home and community-based services to people who might otherwise be institutionalized; (4) the Personal Care Assistance Waiver, which allows disabled Connecticut residents to employ personal care assistants for help with activities essential to daily functioning and greater independence; (5) the Home Care Program for Elders, which helps low-income, frail persons age 65 and older to remain in their home; and (6) the Katie Beckett Waiver, which enables severely disabled children and adults to be cared for at home and be eligible for Medicaid based on the individual's income and assets alone. The state also reported transitions associated with unspecified non-waiver programs:

Transitions in Connecticut					
Waiver or other program	**Number of Individuals Transitioned to Home by Calendar Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Acquired Brain Injury	Not reported	10	21	23	29
MI	Not reported	20	37	23	29

Transitions in Connecticut					
Waiver or other program	**Number of Individuals Transitioned to Home by Calendar Year**				
	2008	**2009**	**2010**	**2011**	**2012**
DDS	Not reported	2	5	13	16
Personal Care Assistance	Not reported	35	74	96	79
Connecticut Home Care Program for Elders	Not reported	51	87	169	230
Katie Beckett	Not reported	Not reported	1	1	3
Non-Waiver programs	Not reported	6	51	52	64

Delaware

Delaware reported that, in conjunction with its MFP initiative, 94 individuals have moved out of long-term care facilities and into their own homes. In addition, 181 individuals with DDs have been diverted from facilities and are living in community neighborhood homes. According to the state, a typical home is four individuals with DDs with rotating staffing. An additional 61 individuals with DDs are in a shared living arrangement, while 13 individuals are in supported housing. Since February 2011, the state has used a Care Transitions Team that is assigned to work with hospitals to assist in discharge planning to focus on creating services that will enable individuals to remain in their homes. In that time, 300 individuals have been referred and 260 of the 300 have returned to their homes with supports and modifications or have been placed in a home better equipped to meet their needs. Delaware also notes that its progress in transitioning can be explained by the development of housing vouchers, subsidies, and bridge funding created in July 2011. These housing measures enabled the state to fund 151 vouchers for individuals with serious and persistent mental illness. The voucher program has been made accessible to all people with disabilities as a core value of the state to reform from a state with a high reliance on facilities to a state committed to a community-based support delivery system.

Hawaii

Hawaii noted that its definition of home includes a house, apartment, condominium, assisted living facility, foster home, care home, or DD domiciliary home. Hawaii also noted that, prior to implementation of MFP in 2009, the state did not collect data on any post-institutionalization living arrangements. Presently, Hawaii only collects this data for individuals who have lived in an institutional setting for 90 days or longer. Hawaii also noted that it no longer has a large state or private institution for ID/DD. Currently, only 80 to 90 institutionalized individuals are living in small, five-bed ICFs for individuals with ID/DD.

Transitions in Hawaii					
Type of Setting or Grant	**Number of Medicaid Beneficiaries Residing in Long-Term Care Institutions for Greater than 90 Days Transitioned into a Home or Community Setting**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing Home	Not applicable	33	58	49	55
Intermediate Care Facility	Not applicable	0	0	2	2
Money Follows the Person Grant	Not applicable	16	38	63	61

Illinois

Illinois reported that it has made several changes to its housing model as a result of three settlements in *Olmstead* class action lawsuits. First, Illinois acknowledged that individuals with serious mental illnesses do not have the opportunity to live independently because of a lack of affordable housing options. As a result, the state created a housing subsidy program for these individuals and has completed the following transitions:

Transitions in Illinois					
Transition From	**Number of Individuals with Serious Mental Illness Transitioned to Permanent Supportive Housing by Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing Home	57	48	136	132	131
State Hospital	1	5	1	2	6
Residential	6	94	135	85	87

In another settlement, Illinois agreed to determine which ICF residents wanted to be served in community integrated settings. The state expects that approximately 1,000 people will indicate a desire to move. To date, the Illinois Department of Human Services has served 216 people who moved to community programs from private ICFs. In addition, under the settlement agreement, the state agreed to move 1,000 people off of the state's community waiting list into community programs by June 30, 2013. An additional 500 people per year will then be served over the next five years. As of January 31, 2013, the Department had served 322 individuals from the community list.

Finally, Illinois settled with a class of individuals who alleged that they were being unnecessarily segregated, institutionalized, and forced to live with numerous other people with disabilities in NFs. Illinois agreed to evaluate an estimated 17,000 members of the class residing in 185 nursing homes. The settlement established benchmarks for the number of transitions.

By the end of the first year of the settlement agreement, 300 class members will transition to community residency. By the end of the second year, a total of 800 class members will transition to community

residency. By the end of the third year after the implementation of the settlement agreement, a total of 1,100 class members should have transitioned. Data collection continues, as the state just began the first year of implementation.

Iowa

Iowa reported the following transitions:

Transitions in Iowa					
Transition From	**Number of Individuals Transitioned to Home by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing facility	352	425	487	556	717
Residential care facility (room and board)	119	146	116	107	93
ICF/ID/DD	64	34	67	56	63

Kentucky

Kentucky reported the following transitions:

Transitions in Kentucky					
Transition From	**Number of Individuals Transitioned to Community by Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing facility	592	504	453	578	555
State nursing facility—institution for mental disease	4	2	1	Not reported	Not reported
ICF/DD	29	45	70	92	41
State psychiatric hospital	50	32	36	Not reported	Not reported
Specialized personal care home	31	40	36	Not reported	Not reported

Maryland

Maryland reported that, since 2008, it has transitioned more than 2,400 Medicaid recipients out of institutions and into the community with needed supports: 473 in 2008, 662 in 2009, 580 in 2010, and 700 in 2011.

Massachusetts

Massachusetts reports the following transitions:

Transitions in Massachusetts					
Transition From	**Number of Medicaid Beneficiaries Residing in Facility Greater than 90 Days Transitioned to a Home by Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing facility	724	897	1,078	1,106	956
ICF/MR	49	23	30	59	70
Psychiatric long-term care units	562	599	714	567	527
Chronic (long-stay) hospitals	378	377	398	353	298

Michigan

Michigan reported that it currently has no public or private ICFs for individuals with ID/DD. A majority of individuals who have a DD or co-occurring mental illness live in a private residence with parents or other family members. These numbers have increased steadily since 2008. The state also reported a steady increase in transitions from NFs to community settings using its Nursing Transitions initiative.

Minnesota

Minnesota noted that the number of people who remain in their own homes has increased since 2008, with over 108,000 individuals remaining in their own home in 2011. Minnesota defines "own home" to mean living arrangements including a person's private residence, being homeless, residing in a car, homeless shelter, hotel/motel, campground, medical hospital for less than 30 days, maternity shelter, chemical dependency halfway house, other halfway house, and detox-only facilities.

Transitions in Minnesota					
Transition From	**Number of Individuals Transitioned to Home by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing facility	284	292	315	306	Not reported
Group homes	255	226	257	252	Not reported
Treatment facilities	82	126	122	115	Not reported
Psychiatric hospital	101	89	49	67	Not reported
ICF/DD	20	25	21	38	Not reported
Institution for mental disease	21	18	16	20	Not reported
Board and Care homes	23	8	18	7	Not reported
Supervised living facility	2	1	7	4	Not reported

Missouri

Missouri reported transitioning 264 individuals with disabilities from facilities into their own homes in 2008, 357 in 2009, 324 in 2010, 387 in 2011, and 320 as of September 2012.

Nebraska

Nebraska reported the following information on discharges from various facilities:

Transitions in Nebraska					
Discharge Facility	**Number of Individuals Discharged by Year**				
	Oct. 2007 to Sept, 2008	**Oct. 2008 to Sept, 2009**	**Oct. 2009 to Sept, 2010**	**Oct. 2010 to Sept, 2011**	**Oct. 2011 to Sept, 2012**
Long-term care psychiatric hospital	116	129	124	83	10
ICF/MR	62	117	86	79	13
Nursing facility	787	845	819	742	734

New Mexico

New Mexico reported on total number of "placements."

Transitions in New Mexico					
Transition From	**Total Number of Placements by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
ICF/MR	278	290	280	286	282
Nursing Facility	5,988	6,007	5,955	6,155	6,098

New York

New York did not report any information on transitions.

Oregon

Oregon reported that the percentage of individuals requiring long-term care and being served in NFs was slowly decreasing, from 18.1 percent in 2008 to 16.3 percent in 2011. Oregon also noted that it no longer has any ICFs for individuals with ID.

Rhode Island

Rhode Island reported that, since 2009, the state has increased the number of adults with DD utilizing community-based shared living arrangement placements from 113 to 224, and has increased efforts to allow individuals to remain in their own homes.

South Dakota

South Dakota did not report any information on transitions.

Tennessee

Tennessee reported that its systems do not identify transitions between non-institutional residential settings in the community (i.e., from community-based "board and care homes" to one's "own home"). The following chart represents (1) the total number of persons who received Medicaid-reimbursed services in an institution (i.e., NF or ICF/ID) at any time during each of the requested fiscal years, and, of those, (2) the total number of persons who were subsequently discharged from the institution during that same year and enrolled in a Medicaid HCBS program, including a §1915(c) waiver or, since 2010, a managed LTSS program operating under the authority of an §1115 waiver. If a person was readmitted to the institution during the same year, the person is not counted as "transitioned" below.

Transitions in Tennessee		
Fiscal Year	**Unduplicated individuals receiving institution**	**Individuals Transitioned to HCBS**
2008	33,064	213
2009	32,461	284
2010	31,999	196
2011	31,432	668
2012	31,457	1,006

Texas

Texas reported the following information on transitions:

Transitions in Texas					
Type of Transition	**Number of Individuals Transitioned by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing facility to 3 bed home	0	0	0	0	0
Nursing facility to 4 bed home	0	0	0	0	2
Nursing facility to community—alternative living/residential care	1,067	528	589	1,039	578
Nursing facility to community—with other waiver participants	98	45	60	88	69
Nursing home to foster/companion care	25	23	13	30	27
Nursing home to own home/family home	2,624	2,371	8	3,361	2,441
ICF/ID to 3 bed home	90	121	211	164	11

Transitions in Texas					
Type of Transition	**Number of Individuals Transitioned by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
ICF/ID to 4 bed home	42	29	94	42	12
ICF/ID to community—alternative living/residential care	0	0	0	0	0
ICF/ID to community—with other waiver participants	0	0	0	0	0
ICF/ID to foster/companion care	62	31	65	28	6
ICF/ID to own home/family home	2	5	4	2	0
State Supported Living Center (SSLC) to 3 bed home	100	134	207	115	62
SSLC to 4 bed home	58	68	85	64	32
SSLC to community—alternative living/residential care	0	0	0	1	0
SSLC to community—with other waiver participants	0	0	0	0	0
SSLC to foster/companion care	23	31	18	11	8
SSLC to own home/family home	5	5	3	2	5
Other type of facility to 3 bed home	12	3	16	11	0
Other type of facility to 4 bed home	7	1	11	9	1
Other type of facility to community—alternative living/residential care	1	2	3	2	5
Other type of facility to community—with other waiver participants	0	0	0	0	1
Other type of facility to foster/companion care	5	3	17	18	0
Other type of facility to own home/family home	2	5	18	26	21

Vermont

Vermont reported the following information on transitions:

Transitions in Vermont					
Type of Transition	**Number of Individuals Transitioned by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
From Nursing Facility to HCBS	309	321	310	332	Not reported
From Nursing Facility to enhanced residential care	65	40	38	46	Not reported

Virginia

Virginia reported transitioning 61 individuals from two state ICFs into the community, as part of a report to DOJ on the status of the state's implementation of an *Olmstead* settlement agreement.

Washington

Washington reported the following information on transitions:

Transitions in Washington					
Transition From	**Number of Individuals Transitioned to Community by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing homes	3,146	3,361	3,776	3,787	Not reported
State psychiatric hospitals	72	187	193	213	Not reported
ICF	184	173	151	149	Not reported

Washington also provided a breakdown of how many of these individuals were transitioned into their own homes:

Transitions in Washington					
Transition From	**Number of Individuals Transitioned to Home by State Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Nursing homes	1,594	1,743	1,970	2,017	Not reported
Two State psychiatric hospitals	7	29	35	35	Not reported
ICF	130	117	107	118	Not reported

West Virginia

West Virginia has not collected data on the people who have transitioned from institutional settings into the community. However, the state reported that it had a limited Transition Navigator Pilot Program, which prevents individuals from having to go into a nursing home or helps them transition out of the nursing home. Under this program, West Virginia reported the following information by fiscal year:

- 2008: 9 transitions/2 diversions
- 2009: 28 transitions/101 diversions
- 2010: 38 transitions/96 diversions
- 2011: 50 transitions/101 diversions
- 2012: 13 transitions/54 diversions

In 2012, the state diverted most of the funds which were being used for the pilot program to use as matching funds for its MFP rebalancing grant.

Wisconsin

Wisconsin reported that the majority of individuals enrolled in a long-term care program reside in a community-based setting or in their own homes. In December 2011, fewer than 30 percent of individuals receiving long-term care services resided in institutions funded through Medicaid. Further, the state reported rebalancing the percentage of individuals receiving HCBS from six percent in 2008 to 67 percent in 2009, 69 percent in 2010, and 72 percent in 2011.

Wyoming

Wyoming reported that its nursing home transition/diversions program, Project Out, transitioned or diverted an average of 160 individuals per year from nursing homes between 2005 and 2012. Wyoming also reported the following transitions:

Transitions in Wyoming					
Transition From	**Number of Individuals Transitioned to Integrated Setting by Fiscal Year**				
	2008	**2009**	**2010**	**2011**	**2012**
Project Out	126	88	23	36	20
Wyoming Retirement Center (skilled nursing facility)	3	8	5	6	0
Wyoming Life Resource Center (ICF)	4	1	4	0	0
Wyoming State Hospital (state operated psychiatric hospital)	Not applicable	117	129	81	103
Board and Care Homes	Not applicable	Not applicable	0	0	0

Section 5: States' *Olmstead* Planning Efforts and Suggestions for Effective Implementation

To gain an understanding of the states' current planning activities, Chairman Harkin requested that the states provide the contents of their *Olmstead* plan for increasing community integration, a description of their strategic planning processes, the extent to which the state plan incorporates new tools created by the federal government, and the extent to which their goals have been met. The Chairman asked the states (a) whether they have any recommendations to make *Olmstead* implementation easier and (b) to share any successful strategies for implementation.

Olmstead Plans

Fourteen states provided information about their publically available *Olmstead* plans.[101] In addition, 11 states either (1) indicated that they are in the process of developing formal plans or (2) submitted information in their response letter showing a strategic approach to *Olmstead* compliance, such as through other planning and reporting efforts, enacting legislation, creating a task force, or actions taken pursuant to settlement agreements.[102] The states' planning efforts vary considerably, ranging from simple lists of recommendations to more comprehensive action plans.[103] Some states organized their plans around guiding principles. For example:

- Arizona's plan is structured around the following: person-centered care management, consistency of services, available and accessible services, use of the most integrated setting, and collaboration with stakeholders.

- Arkansas produced its *Olmstead* plan according to the following key areas of need: additional resources to support system improvements, increased community capacity, new approaches to service provision, and increased consumer-directed care.

- Colorado's planning team identified strategies to address key issues, including suitable financing, increasing housing options, expanding the current array of services, and better informing the community about services available for people with disabilities.

- Hawaii's plan is focused around the following principle: each individual will be able to locate housing, acquire personal support personnel, use transportation, and engage in employment to sustain community-based living.

Other states' plans included specific goals. For example:

- Connecticut's goal is to increase the incidence of individuals receiving community-based LTSS to 75 percent by 2025.

- As result of a 2011 settlement agreement stemming from *Olmstead* litigation, Delaware committed to providing intensive community-based treatment and offering at least 650 housing vouchers or subsidies to allow people to obtain stable, integrated housing. According to the most recent court monitor report, Delaware "is largely meeting its benchmarks and it is making significant, sometimes ground-breaking, progress in retooling its systems in fulfillment of the ADA."

- Tennessee implemented its CHOICES programs as part of its plan to increase access to HCBS for individuals with physical disabilities. Since the program's inception in 2010, the number of persons enrolled in HCBS has increased by nearly 150 percent and the number of persons enrolled in NFs has decreased by more than 12 percent.

- Oregon noted that a key strategy of its plan, the Adult Mental Health Initiative, has allowed the state to transition 494 individuals to lower levels of care during the initiative's first 10 months.

Although some plans contained these types of specific principles and goals, many of the plans lacked detailed, enforceable benchmarks. In addition, three states—Alaska, South Dakota, and Rhode Island—did not provide any strategic planning information as part of their response letters, although each provided limited information about their progress serving individuals with disabilities in integrated settings. It is important to note that a detailed plan is not necessarily an effective plan; it is not possible to determine whether states have been successful in promoting the inclusion of people with disabilities into the community without fully assessing outcomes of their planning efforts. Nonetheless, a successful plan should include a strategy directed at consistently transitioning people with all types of disabilities out of institutional settings and into living situations that allow individuals to exercise the autonomy and the rights guaranteed by the Constitution and the ADA in a way that is cost-effective for that state. See Appendix 2 for highlights from the responding states' *Olmstead* planning efforts.

Suggestions for Effective Implementation

States offered many suggestions, most notably on the following broad topics.

- **Employment.** Many states noted that one of the biggest barriers for individuals moving from facilities is employment. Washington noted that employment is one of the most effective ways to help people who rely on human services avoid crisis, homelessness, and reduced capacity. Yet federal rules require people who apply for benefits because of disability to prove that they are "unable to work at a substantial gainful activity level." Michigan cited success with its Ticket to Work and Work Incentives Act of 1999 and its Freedom to Work/Medicaid Buy-in program. Enrollment has grown from less than 300 in early 2006 to more than 7,000 individuals in 2012. Individuals are earning more money and paying greater portions of their medical costs. Wyoming noted that it convened a state Integrated Employment Team in 2012 to begin developing a comprehensive strategic plan for increasing employment outcomes for people with DD.

- **Housing.** States commented that affordable and accessible housing is key to assisting individuals in transitioning from nursing homes and other types of institutions. California and New Mexico advocated increasing federal incentives for housing. Maryland advocates continued collaboration between CMS and HUD to expand affordable housing options for people in need of long-term support. Maryland noted that, through this partnership, HUD could designate funding for the rehabilitation of vacant housing stock to create more affordable accessible housing options to support transitions from institutional settings, issue additional vouchers, and allow nonprofit organizations to access vouchers if the applicable public housing authority chooses not to seek the new vouchers.

- **Community Participation.** Many states commented that community participation was critical to the strategic planning process. For example, Arkansas noted that it has been most effective to develop task forces to assess the needs of individuals with disabilities across systems, whereas Iowa commented that engaging key stakeholders, especially persons with disabilities and their

families, friends, and advocates, has been instrumental in moving toward community integration—“a life in the community for everyone."

- **Aging and Disability Resource Centers (ADRC).** Several states advocated continued and/or enhanced support for aging and disability resource centers, which provide information on all aspects of life related to aging or living with a disability. For example, California suggested establishing a dedicated funding stream to facilitate expansion of ADRCs. Iowa commented that strengthening options for counseling services through ADRCs will promote ADRC sustainability.

- **Funding and Federal Financial Incentives.** Many states requested increased financial incentives. California suggested expanding the federal financial participation for HCBS and removing state match requirements for new federal assistance. Kentucky recommended reinstating the increased Federal Medical Assistance Percentage and instituting a higher federal match for community-based psychosocial treatments and interventions to incentivize community-based services, instead of inpatient institutional services. New Mexico advocated for more flexibility to provide adequate services to urban, rural, and frontier areas.

- **New Federal HCBS Options.** Alaska commented that removing the institutional level of care requirement from CFC would remove barriers to integration for individuals who have functional limitations but do not require hands-on nursing assistance. Kentucky suggested expanding CFC to include all community services to create a "supermarket" of services for people based on functional need, rather than diagnosis. Several states commented that all states should be eligible for the increased FMAP accompanying BIP, not just those that rely heavily on institutions.

See Appendix 3 for highlights from the responding states’ suggestions for effective *Olmstead* implementation.

Section 6: Recommendations

The Committee developed the following recommendations for moving forward:

- Congress should amend the ADA to clarify and strengthen the law's integration mandate in a manner that accelerates *Olmstead* implementation and clarifies that every individual who is eligible for LTSS under Medicaid has a federally protected right to a real choice in how they receive services and supports.

- Congress should amend the Medicaid statute to end the institutional bias in the Medicaid program by requiring every state that participates in the Medicaid program to pay for HCBS, just as every state is required to pay for nursing homes, for those who are eligible.

- State and federal efforts should focus on helping people live in their own homes. Virtually all people with disabilities can live in their own apartment or house with adequate supports. Accordingly, for virtually all people with disabilities, the most integrated setting appropriate is their own home.

- Congress should require clear and uniform annual reporting of the number of individuals served in the community and in institutions, together with the number of individuals transitioned and the type of HCBS living situation into which they are transitioned.

- States should more fully examine the enhanced federal funding available under new federal programs designed to encourage states to transition more individuals into community-based settings and shift away from waivers, which allow states to set caps on the number of individuals served. Other federal programs – including the Community First Choice Option (CFC), the Balancing Incentives Program (BIP), and the 1915(i) option – provide significant additional federal resources in exchange for requiring the state to serve all of the eligible populations. Congress and CMS should help states to conduct analyses of the unmet need in individual states.

- CMS should finalize its proposed rule defining what type of setting qualifies as home and community-based.

- DOJ should expand its *Olmstead* enforcement efforts, to include investigations of segregated employment settings for individuals with disabilities and the inappropriate placement of young people with disabilities in nursing homes, especially in states that are in the bottom quartile of spending on HCBS and/or for discreet subpopulations.

- CMS, the Administration on Community Living at the Department of Health and Human Services (HHS), the Office for Civil Rights at HHS, the Department of Housing and Urban Development (HUD), the Civil Rights Division at the Department of Justice (DOJ), the National Council on Disability (NCD), and the National Institute on Disability and Rehabilitation Research should create a high-level interagency task force within six months of the issuance of this report on *Olmstead* implementation and should deliver a consistent message to states about their *Olmstead* obligations and the federally created tools that can help them comply with the decision.

    - The task force described above should review and comment on proposed federal regulations and proposed subregulatory guidance that have the potential to impact *Olmstead* implementation.

- The task force described above should collaborate with the National Governors Association (NGA) and other appropriate entities to create a technical assistance program for states that helps them to develop and implement *Olmstead* plans.

- CMS should require incremental state spending goals for national Medicaid LTSS for 2015, 2020, and 2025 to ensure that the proportion of spending on HCBS continues to increase. Congress should increase the federal share of Medicaid expenditures for states that achieve these benchmarks and reduce the federal share for states that do not.

  - To help accelerate the states' progress, the Secretaries of HHS and HUD should write to the governors to inform them how they can best leverage the CFC Option, rebalancing initiatives, and federal housing subsidies as they provide services in the community.

- The Administration on Community Living at HHS and HUD should collaborate to develop and implement a national action plan to expand access to affordable, integrated, accessible, and "scattered site" housing for people with significant disabilities, consistent with the *Olmstead* decision.

- DOJ should create an *Olmstead* impact analysis instrument that can be used as states make significant changes in their Medicaid programs, including the following: implementation of managed care for LTSS, implementation of Medicaid expansions under the Affordable Care Act (ACA), and implementation of cuts in Medicaid and housing subsidies during periods of fiscal downturn.

- NCD should review the various federal tools that have been created to assist states in moving away from institutions and toward HCBS. NCD should make recommendations to the Administration and Congress that will make it easier for state legislatures and Medicaid officials to understand their options, and to reward states that are proactive and avoid rewarding states that have been dragging their feet on *Olmstead* implementation.

  - The NCD review described above should include recommendations to clarify the federal definition of "home and community-based" and to create a consolidated, streamlined federal reporting mechanism that would enable states to receive apples-to-apples comparisons with other states and allow federal officials and stakeholders to have timely, accurate information about key indicators in *Olmstead* implementation.

Appendix 1: Overall Spending Information and Expansion in Capacity

The responding states chose to present information on spending in a variety of different ways. For example, several states provided an exact breakdown of how much of the state's budget was spent on HCBS during specific years or a range of years. Other states reported total Medicaid spending broken down into how much was spent in a different setting or program, while others reported spending information associated with where individuals receive services. In general, the responses confirm that state spending on HCBS varies widely.

With regard to expansion in capacity to serve, a majority of the responding states reported an increased capacity to serve individuals in the community, through either an overall increase in spending on HCBS from 2008 to 2011 and/or an increase in the number of individuals served by HCBS during the same period.[104] However, states have not demonstrated significant progress expanding their capacity to serve individuals in their own homes. Although Chairman Harkin's letter specifically asked for data on expansion of capacity to serve individuals in the home, only seven states provided this information.[105]

Highlights of State Spending Data

Alabama

Alabama reported the following spending data:

Alabama Spending	
Setting	**State Dollars Allocated for FY12 (in millions)**
ICF/ID	$4.1
Boarding Homes	None
Long-Term Care Psychiatric Hospitals	$107
ID Group Homes	$67
Mental Illness Group Homes	$23
Mental Illness Foster Homes	$1.8
Mental Illness Local Crisis/Acute Care	$16
ID Living at Home Waiver	$1.9
ID HCBS Waiver	$29.7
ID Community Supports	$1.8
Mental Illness Supportive Housing	$2.5

With regard to expanded capacity to provide HCBS, Alabama reported increased spending on its §1915(c) waivers from 2008 to 2012 and also reported increased spending for other community supports, including its supported housing programs and its peer supports program.

Alaska

Alaska reported the following spending data:

Alaska Spending	
Setting	**Approximate State Dollars Spent During State Fiscal Year 2012 (in millions)**
Skilled Nursing Facilities	$48
ICF/ID/DD	$1
Psychiatric Hospitals	Not available
Supported Housing (behavioral health assisted living)	$2.7
Residential Psychiatric Treatment (child and adolescent)	$36
Assisted Living Homes	$24
Group Homes	$26.5
Other In-home Services	$125

Alaska has increased spending and the number of individuals served for all of its §1915(c) waivers and the state Personal Care Attendant Services since 2008. For example, in 2008, Alaska spent 72 million dollars providing services through §1915(c) waivers and $35.6 million through the personal care services option. In 2011, the state spent $155 million for §1915(c) waiver services and $56.5 million on the personal care services option. The state also increased the population served by the §1915(c) waivers by 2,173 individuals and by the personal care services option by 1,407 individuals.

Arizona

Arizona reported that over 95 percent of individuals with DD in the state receive services in the community. For elderly or physically disabled individuals, 49 percent receive services in their own homes, 25 percent in alternative residences, and 26 percent in NFs. The state also noted that approximately 84 percent of its long-term care population is currently served in HCBS settings. With regard to spending, the state reported on total funds allocated, which includes an FMAP of 33 percent state funds and 67 percent federal funds, for the following:

Arizona Total Spending	
Setting	**Total Funds Allocated for Fiscal Year 2013 (in millions)**
Skilled Nursing Facilities	$2.8
Intermediate Care Facilities	$36.9
Group/Developmental Home	$290.4
Supported Living	$26.9

Arizona Total Spending	
Setting	**Total Funds Allocated for Fiscal Year 2013 (in millions)**
Family/Own Home	$398.8

Arizona also reported state spending information on group and developmental homes and psychiatric hospital inpatient services.

Arizona State Spending	
Setting	**State Funds Allocated for Fiscal Year 2013 (in millions)**
Permanent Supported Housing	$11.4
Psychiatric Hospital-Inpatient Services	$7.8

Arizona reported that "[s]ince 1998, Arizona's HCBS placement percentage has increased by over [30] percent, which has resulted in $300 million in savings." Arizona uses a statewide §1115 waiver to provide services to individuals. The waiver pays for all services, either HCBS or in institutions, such that all state spending is disbursed through the waiver. From 2008 to 2012, spending on HCBS increased, spending on institutions decreased, and the number of individuals served in HCBS increased and in institutional settings decreased:

Arizona Expansion in Capacity				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1115 Waiver	Individuals Meeting Nursing Home Level of Care			
	$304,752,826	$303,319,435	23,698	25,693
	Individuals Meeting ICF Level of Care			
	$265,962,248	$272,149,901	20,486	24,858
Nursing Facilities	$133,309,023	$129,782,226	7,679	6,897
Intermediate Care Facilities	$9,546,075	$9,035,145	410	171

Arkansas

Arkansas provided data on expected spending for state fiscal year 2013 and projected spending $151.7 million (52.5 percent) of the state Medicaid budget on HCBS and $137.1 million (47.4 percent) on institution.

Arkansas Spending	
Setting	**Approximate State Medicaid Spending Projections for Fiscal Year 2013**
Private Nursing Home	$81,057,044
Public Nursing Home	Not reported
Infant Infirmary	$4,761,417
Human Development Centers	Not reported
10 Bed ICF/MR	$3,141,788
Inpatient Psychiatric	$48, 155, 466

Arkansas also reported spending breakdowns for its §1915(c) HCBS waivers and other non-waiver HCBS options. Specifically, Arkansas provided data about spending under its Alternative Community Services Waiver, which provides HCBS to a limited number of individuals with disabilities; the Elder Choices Waiver; the Alternatives for Adults with Physical Disabilities Waiver; and the Living Choices Assisted Living Waiver. Arkansas also provided data on its Independent Choices program, which provides a cash allowance for seniors and disabled individuals to direct their own care, and its Developmental Day Treatment Clinic Services program, which provides a range of comprehensive services to individuals with ID/DD in a clinic setting.

Arkansas Waiver and Non-Waiver Spending	
Setting	**Approximate State Medicaid Spending Projections for Fiscal Year 2013 (in millions)**
Alternative Community Services Waiver	$55, 138,062
Elder Choices	$21,481, 885
Adults with Physical Disabilities	$13,009, 951
Living Choices Assisted Living	$4,442,866
Non-waiver Independent Choices Program	$8,724,201
Developmental Day Treatment Clinic Services	$48,890,519

Arkansas reported that the state has provided an additional $1.1 million of services and supports to children with severe to moderate behavioral health care at risk of removal from their home and community. The state also increased both spending and the number of individuals served in several §1915(c) waivers. Specifically, from 2008 to 2011, Arkansas increased Elder Choices spending by $22.7 million to serve an additional 683 individuals. Further, from 2008 to 2012, Arkansas increased Alternatives for Adults with Physical Disabilities spending by $8.6 million to serve an additional 800 individuals. Finally, Arkansas increased Alternative Community Services spending by $55.6 million to serve an additional 273 individuals.

California

California reported the following state spending information:

California State Spending	
Setting	**State Funds Budgeted for State Fiscal Year 2013**
Nursing Facilities	$1,879,725,160
ICF/DD	$162,013,844

California also provided the total amount, including federal dollars, budgeted for the following:

California Total Spending	
Setting	**Total Funds Budgeted for State Fiscal Year 2013**
Civil Commitments to State Hospitals	$1,111,977,014
In-hHome Supportive Services	$5,101,124,625
Community-Based Adult Services	$288,426,000
Multipurpose Senior Services Program	$40,464,000

With regard to expanded capacity to provide HCBS since 2008, California reported the following increases in individuals served for its various §1915(c) waivers:

- the AIDS Waiver increased in capacity from serving 3,720 individuals in 2008 to 4,410 individuals in 2012;
- the Assisted Living Waiver increased in capacity from serving 1,300 individuals when it was created in 2009 to 2,920 in 2012;
- the HCBS waiver for the Developmentally Disabled Waiver increased in capacity from serving 80,000 individuals in 2008 to 105,000 in 2012;
- the Nursing Facility/Acute Hospital Waiver increased in capacity from serving 2,552 individuals in 2008 to 3,192 in 2012;
- the Developmentally Disabled/Continuous Nursing Care Waiver increased in capacity from serving 72 individuals when it was created in 2010 to 84 in 2012;
- the Pediatric Palliative Care Waiver increased in capacity from serving 801 individuals when it was created in 2010 to 1,802 in 2012; and
- the San Francisco Community Living Support Benefit Waiver increased in capacity from serving 3,720 individuals in 2008 to 4,410 in 2012.

Colorado

Colorado provided spending data for federal fiscal years 2010 and 2011. The state reported spending $551.4 million (50.5 percent) on HCBS and $540.1 million (49.5 percent) on institution. The state reported the following breakdown of expenditures:

Colorado Spending	
Setting	**State Expenditures for Federal Fiscal Year 2010 to 2011**
Nursing Homes	$251,173,006
ICF/ID/DD	$18,883,117
Board and Care Homes	$21,200,240
Psychiatric Facilities	$1,227,158
Group Homes	$133,231,100
Own Homes	$121,292,366

Colorado also reported spending data on alternative placements to state psychiatric hospitals. According to the state, these alternatives include other institution-like settings and options that fall between an institutional level of care and the least restrictive environments.

Colorado Spending on Alternative Settings	
Setting	**State Budget Amount for State Fiscal Year 2011 to 2012**
Acute Residential Facility	$117,274
24 Hour Hospitalization and Transitional Services	$117,274
Integrated Treatment and Intensive Treatment Houses	$215,051
Assisted Living Facility	$375,586
Family Care Homes	$85,958
Senior Housing Options	$104,120

Colorado reported an approximately three percent increase in funding for HCBS from 2008 to 2012. The number of people receiving HCBS also increased by 4,276 individuals over that same time period. Also during that time, the number of individuals served in institutions decreased by 1,378 individuals. Further, the state reported increasing the capacities of several §1915(c) waivers by increasing the number of individuals that the waiver could serve and by appropriating additional funds; increasing the number of housing supports in 2010, 2011, and 2012; and increasing the number of individuals residing in supported housing or other independent living arrangements from 60,368 in 2008 to 75,861 in 2012.

Connecticut

Connecticut reported state fiscal year expenditures for a variety of different programs and waivers for the blind and disabled. In total, Connecticut reported about $1.4 billion dollars in state expenditures. From 2008 to 2012, Connecticut reported that spending on HCBS increased and spending on institutions decreased. In addition, the number of individuals served in HCBS increased and in institutional settings decreased.

Connecticut Expansion in Capacity				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$89,394,024	$115,506,570	12,899	11,775
	Individuals Meeting ICF Level of Care			
	$240,077,190	$319,398,133	8,090	8,770
Money Follows the Person	Not applicable	$3,155,328	Not applicable	450
Nursing Facilities	$621,259,227	$609,479,665	17,466	16,748
Intermediate Care Facilities	$240,452,835	$143,555,328	1,129	1,004

Delaware

Delaware reported that, in April 2012, 62 percent of its long-term care population resided in nursing homes and 87 to 90 percent of long-term care expenditures funded nursing home care.

Delaware Spending	
Setting	**State Dollars To Be Spent in State Fiscal Year 2012**
State Administered Long-Term Care Facilities—Medicaid	$11,355,600
State Administered Uncompensated Care Beds	$18,926,700
Medicaid Private Long-Term Care Beds	$77,337,300 (a portion of this is to be spent in 2013)
Intermediate Care Facilities—Private Medicaid Beds	$3,952,000
Intermediate Care Facilities—State Facility	$10,600,700
Psychiatric Hospital	$36 300,600
Shared Living	$1,365,000
Group Homes (average size 4 individuals)	$46,830,900

Delaware Spending	
Setting	**State Dollars To Be Spent in State Fiscal Year 2012**
Supported Housing (state rental assistance program)	$2,304,000

The state also showed an increased capacity to serve individuals with disabilities in their homes since 2008. Specifically, Delaware reported that a recent change to a §1115 waiver was designed to rebalance the state's long-term care system in favor of HCBS. The state increased the housing supports available to individuals, including an additional $2.5 million to provide housing supports for 75 individuals per year and a minimum of $1.8 million of additional funding for housing vouchers. Delaware also reports that, since 2008, the state has increased its capacity to serve individuals with ID/DD by moving 255 individuals into the community. As a result of the change to its §1115 waiver, Delaware projects modest savings of two million dollars by the end of the program's first year.

Hawaii

Hawaii stated that overall state expenditures on HCBS exceeded spending on institution. Specifically, Hawaii reported the following expenditures for the first 10 months of fiscal year 2012:

Hawaii Spending	
Setting	**Actual 10 Month State Expenditures from 10/1/11 to 7/31/2012**
Nursing Homes	$53,014,465
ICF/MR	$3,698,679
Psychiatric Hospitals	Not applicable
HCBS Waivers	$74,467, 407

Hawaii also reported that spending on HCBS has increased since 2008. In 2008, Hawaii spent $68.3 million to provide HCBS, and, in 2012, the state spent $89.4 million—$21.1 million in additional funds. In addition, the number of individuals receiving HCBS increased from 2,110 in 2008 to 4,572 in 2012, whereas the number of individuals receiving services in institutions decreased from 2,840 in 2008 to 2,476 in 2012.

Illinois

Illinois provided total spending data for a full year ending on January 29, 2013.

Illinois Spending	
Setting	**Total Estimated Liability as of 1/29/31**
DD Community Programs	$768,999.50
ICF/DD	$389,160.80
Mental Health Supported Housing	$11,756.30

Illinois Spending	
Setting	**Total Estimated Liability as of 1/29/31**
Mental Health State Operated Hospitals	$199,700.00
Mental Health Residential	$51,900.00
Home Services Program	$576,201.00
Community Reintegration	$2,907.20

Illinois reported that, since 2008, the state has taken several steps to expand the supply of permanent supportive housing, including:

- implementing the Low Income Housing Tax Credit Targeted Program for Persons with Disabilities, such that "689 rental units affordable to disabled persons with incomes at or below [30] percent of area median income have been created under the Targeted Program in community integrated settings";
- developing 1,226 permanent supportive housing units for persons with disabilities and veterans through the use of $70 million of state capital bond funding;
- providing $10 million in rental subsidies for persons with disabilities; and
- utilizing $12 million to fund 19 not-for-profit organizations to conduct home modifications for homeowners and renters to enable persons with physical disabilities to maintain their occupancy in their existing homes and to prevent unnecessary placement in long-term care facilities.

Iowa

Iowa provided estimated spending data for 2013 and projects spending 52 percent of the LTSS Medicaid budget on institution and 48.11 percent for HCBS in 2013.

Iowa Spending	
Setting	**State Dollars to be Spent in State Fiscal Year 2013 (in millions)**
Non-Institutional Expenditures	$888,891,420
Institutional Expenditures	$958,831,066

From 2008 to 2012, spending on all HCBS options increased and spending on institutions increased, as did the number of individuals served by HCBS. Iowa reports that these HCBS capacity building efforts will continue as the "legislature continues to appropriate increased funding to support expansion of community services through Medicaid HCBS [w]aivers."

Iowa Expansion in Capacity				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$26,083,889	$31,671,703	12,829	12,845
	Individuals Meeting ICF Level of Care			
	$118,365,154	$149,828,318	14,384	15,742
§1915(i)	$12,770,898	$28,478,247	3,127	5,362
Money Follows the Person	Not applicable	$935,506	Not applicable	119
Nursing Facilities	$167,643,203	$208,039,772	19,005	17,772
Intermediate Care Facilities	$101,128,589	$109,715,268	2,294	2,163

Kentucky

Kentucky reported the following allocations for state fiscal year 2013:

Kentucky Spending	
Setting	**State Dollars Allocated for State Fiscal Year 2013 (in millions)**
Nursing Facilities	$257,648,000
State Nursing Facilities	$15,443,000
ICF/DD	$39,533,000
Psychiatric Facilities	$23,705,000
State Psychiatric Facilities	$107,474,000
Specialized Personal Care Homes	$67,111,000
Group Homes (DD)	$7,135,000
State Supplementation for Individuals Residing in Personal Care Homes	$16,900,000
Money Follows the Person Services	$2,712,000
Model Waiver II Ventilator Dependent	$,185,000
Home and Community Based for Aged/Disabled Waiver	$7,608,000
Acquired Brain Injury - Acute Waiver	$5,873,000
Acquired Brain Injury- Long-Term Care Waiver	$3,648,000

Kentucky Spending	
Setting	**State Dollars Allocated for State Fiscal Year 2013 (in millions)**
Michelle P Waiver	$48,605,000
Supports for Community Living Waiver	$81,198,000
Traumatic Brain Injury Waiver	$3,405,000
Severe Mental Illness	$600,000
Supported Housing	$2,598,000
HomeCare	$17,032,000
Adult Day Social Care	$2,755,000
Adult Day Health Care	$19,091,000
Personal Care Attendant Program	$4,140,000
Hart Supportive Living	$6,907,000

Kentucky also provided data on the state's expanded capacity to serve individuals in their own homes for 2008 through 2012. State spending to serve individuals in their own homes through the Kentucky Department of Medicaid Services increased a cumulative 65 percent from 2008 to 2012. Further, the number of individuals served in their own homes increased by a cumulative 39 percent from 2008 to 2012.

Maryland

Maryland reported the following state spending information:

Maryland Spending	
Setting	**State Dollars Spent in Fiscal Year 2011, ending June 30, 2011 (in millions)**
Nursing Homes	$580,236,113
ICF/ID/DD	$13,311,458
Psychiatric Hospitals	$11,106,874
Group Homes	$278,455,652
Individual Homes	$287,934,715

From 2008 to 2012, spending on HCBS and spending on NFs increased, while spending on ICFs decreased. The number of individuals served in HCBS increased and the number served in institutions decreased. Maryland also reported that, since 2008, the state has expanded capacity by investing state

funds to improve MFP activities, expanding 1915(c) waiver slots, adding services to existing programs, and increasing outreach to potentially eligible individuals.

Maryland Expansion in Capacity				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$49,897,144	$104,931,732	4,228	9,597
	Individuals Meeting ICF Level of Care			
	$277,101,872	$359,394,506	12,152	13,847
Money Follows the Person	$283,797	$5,190,971	162	320
Personal Care Services Option	$11,876,768	$15,517,024	4,324	5,147
Nursing Facilities	$543,657,441	$577,456,388	22,727	22,333
Intermediate Care Facilities	$32,658,565	$14,749,029	310	140

Massachusetts

Massachusetts reported the following spending data:

Massachusetts Spending	
Setting	**Projected State Dollars to be Spent in Fiscal Year 2013 (in millions)**
Nursing Homes	$1,550
ICF	$133
Psychiatric Hospitals	$167
Community Settings	$2,444
Supportive Housing in Elderly/Disabled Public Housing	$4

Massachusetts also reported expanding capacity in its §1915(c) HCBS waivers by approximately 6,000 individuals since 2008 and expanding total Medicaid spending for the waivers by $290 million from 2008 to 2009, $173 million from 2009 to 2010, and $103 million from 2010 to 2012. The state projects an increase in spending for HCBS by an additional $130 million from 2011 to 2012 and $139 million from 2012 to 2013. The state also expanded access to supportive housing by creating 31 supportive housing sites for elderly or disabled individuals, using state funds of more than $4 million.

Michigan

Michigan reported the following spending data:

Michigan Spending	
Setting	**Estimated State Dollars Expected to be Spent in Fiscal Year 2012**
Nursing Facility	$600.8 million
Psychiatric Hospital	$161,981,700
Community Settings – MI Choice Waiver	$100,232,200
Community Settings – Adult Home Help Waiver	$117.2 million
Community Settings – Managed Specialty Supports & Services Plan and Habilitations Supports Waiver	$165,287,590
Community Settings – Other Community Programs	$9.4 million

Michigan reported increased funding for the MI Choice Waiver, which assists individuals who would otherwise be institutionalized, by an estimated $11.8 million in 2013. The state also provided $40.7 million to support individuals transitioning from NFs. After closing its last ICF in 2009, the state provided additional funding to the Habilitation Supports Waiver to enable the ICF's last residents to transition into the community. The state also reported creating a monetary incentive for provider networks that show the greatest improvement in the overall number of individuals with disabilities served that are living in a private residence.

Minnesota

Minnesota reported the following spending data:

Minnesota Spending	
Setting	**State Dollars Spent in State Fiscal Year 2011**
Nursing Facilities	$50,056,644
ICF/DD	$64,203,703
Institution for Mental Diseases (facility of 17 beds or more engaged in providing care of people with mental diseases)	$7,443,974
Board and Care Homes	$2,792,675
Psychiatric Hospitals	$32,854,227
Group Homes	$542,418,377
Supervised Living Facility	$68,645,635
Own Homes	$413,859,087

Spending on most HCBS increased from 2008 to 2012 and spending on institutions decreased. The number of individuals served in most HCBS programs increased and the number of individuals served in institutional settings decreased:

Minnesota Expansion in Capacity[a]				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$322,669,250	$464,575,804	31,723	43,045
	Individuals Meeting ICF Level of Care			
	$462,599,341	$506,347,541	13,971	15,445
Alternative Care	$29,726,077	$27,121,470	3,371	2,983
Personal Care Services Option	$225,024,967	$287,165,791	16,746	23,679
Private Duty Nursing	$32,658,676	$47,604,127	477	612
Home Health	$12,623,320	$11,227,962	5,116	5,015
Consumer Support Grant	$11,945,494	$15,626,848	1,040	1,541
Family Support Grant	$5,088,218	$4,362,500	1,628	1,628
Semi-Independent Living Services	$8,058,000	$8,490,500	1,552	1,552
Nursing Facilities	$397,184,408	$382,123,268	19,468	17,053
Intermediate Care Facilities	$67,302,494	$63,026,282	1,850	1,720

[a] Minnesota reported on a number of state-funded grant programs; for example: the Consumer Support Grant allows individual meeting an ICF level of care to purchase supports in a self-directed manner and the family support grant provides a grant to family members to support a child with disabilities meeting the ICF level of care.

Missouri

Missouri reported the following spending data:

Missouri Spending	
Setting	**State Dollars Spent in Federal Fiscal Year 2012 (in millions)**
Nursing Home	$101.1
ICF	$32.5
Board/Care/Group Home	$41.5
Psychiatric Hospitals	$161.3
Own Home	$268.6

Missouri reported expanding the state's capacity to serve individuals with disabilities in their own homes by spending $33.2 million in additional state funds in 2008, $26.8 million in 2009, $43.7 million in 2010, $29.4 million in 2011, and $55.7 million in 2012. The overall number of individuals served in their own homes also increased from 2008 to 2012.

Nebraska

Nebraska reported the following spending data:

Nebraska Spending	
Setting	**Estimated State Dollars Spent from October 2011 - September 2012**
Nursing Facilities	$61,067,485
ICFs	$23,828,544
Long-Term Care at Psychiatric Hospital	$596,565
Group Homes	$68,107,622
Homes	$179,795,453
Supportive Housing	$2,100,299
Other	$31,999,491

Nebraska reported that the state has enacted regulations to encourage individuals to live in their own homes. The state also expanded access to housing assistance for adults with serious mental illness through the state-funded Housing-Related Assistance program. The program is limited to extremely low-income individuals with serious mental illness with housing problems. Nebraska did not provide spending data for this expansion effort, but the state reported serving 717 additional individuals in 2008, 823 in 2009, 845 in 2010, 818 in 2011, and 825 in 2012.

New Mexico

New Mexico reported that it generally spent 61 to 69 percent of the state's Medicaid long-term care budget on HCBS. The state reported the following spending information for its §1915(c) waivers and PCS option:

New Mexico Spending	
Setting	**State Dollars Spent in State Fiscal Year 2012—July 1, 2011 to June 30, 2012 (in millions)**
HIV/AIDS Waiver	$237,785 (thousand)
Brain Injured Waiver	$4.3
Disabled and Elderly Waiver	$29.6
Personal Care Option	$178.4

New Mexico Spending	
Setting	**State Dollars Spent in State Fiscal Year 2012—July 1, 2011 to June 30, 2012 (in millions)**
Program of All-Inclusive Care for the Elderly	$3.4
Nursing Facilities	$44.3
Developmental Disabilities Waiver	$92.5
Medically Fragile Waiver	$2
ICFs	$7.8

From 2008 to 2012, spending on HCBS programs increased and spending on institutions decreased. The number of individuals served in HCBS programs also increased.

New Mexico Expansion in Capacity				
Program	**State Spending[a]**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$26,363,956	$33,332,956	4,110	3,398
	Individuals Meeting ICF Level of Care			
	$85,645,616	$92,462,770	3,988	4,079
Personal Care Services Option	$89,280,420	$178,380,196	12,920	17,656
Nursing Facilities	$56,760,779	$44,336,116	5,986	6,098
Intermediate Care Facilities	$6,778,393	$7,824,983	278	282

[a] New Mexico's response provided spending data in two different forms and the spending data was not consistent. These figures are taken from the charts provided in Attachment C of their letter since those figures included institutional spending.

New York

New York reported the following spending data:

New York Spending	
Setting	**State Dollars Spent in Fiscal Year 2011**
Nursing Facility – Long-Term Home Health Care Program	$575,455,666
Nursing Home Transition and Diversion Medicaid Waiver	$48,326,290
Traumatic Brain Injury Waiver	$90,184,702

New York Spending	
Setting	**State Dollars Spent in Fiscal Year 2011**
Care at Home I/II Waiver	$37,690,410
Money Follows the Person	$4,118,234
Personal Care Services for Individuals Meeting Nursing Home Level of Care	$742,002,296
Consumer Directed Personal Assistance Program	$155,650,629
Nursing Facilities	$2,870,361,280
Care at Home III Waiver	$4,977,144
Office for People with DD Waiver	$4,508,281
Care at Home IV Waiver	$4,705,597
Bridges to Health for Children who are Medically Fragile Waiver	$3,283,045
Bridges to Health for Children with Severe Emotional Distress Waiver	$55,897,157
Bridges to Health for Children with DD	$6,539,250
Office of Mental Health – Severe Emotional Distress Waiver	$62,334,744
ICFs	$1,531,123,197

From 2008 to 2011, spending on most HCBS programs increased and spending on NFs decreased. The number of individuals served by most HCBS programs and in institutional settings increased:

New York Expansion in Capacity				
Program	**State Spending**		**Individuals Served/Eligible**	
	2008	**2011**	**2008**	**2011**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$668,090,972	$751,657,068	29,081/29,523	33,747 /34,036
	Individuals Meeting ICF Level of Care			
	$70,187,240	$142,245,218	2,961/3,014	7,540/7,674
Money Follows the Person	Not applicable	$4,118,234	Not applicable	240
Personal Care Services Option	$975,266,458	$742,002,296	69,073/ 69,073	57,881/ 57,881

New York Expansion in Capacity				
Program	**State Spending**		**Individuals Served/Eligible**	
	2008	**2011**	**2008**	**2011**
Consumer Directed Personal Assistance Program	$142,958,961	$155,650,629	9,112/ 9,112	10,709/ 10,709
Nursing Facilities	$2,888,025,360	$2,870,361,280	151,307/ 151,307	357,304/ 357,304
Intermediate Care Facilities	Not provided	$1,531,123,197	Not provided	7,841/ 7,841

Oregon

Oregon reported that it was unable to isolate the amount spent serving individuals with disabilities in NFs from the number of elderly and disabled individuals served in NFs and, therefore, did not provide spending data for NFs. The state reported the following spending data:

Oregon Spending	
Setting	**State Dollars Spent in Fiscal Year 2012**
ID/DD– Group Homes, Foster Care, etc.	$152,920,639
ID/DD– In-Home Supports (individual or family home)	$26,744,532
Individuals served by the Addictions and Mental Health Division – Psychiatric Hospitals	$154,547,105
Individuals served by the Addictions and Mental Health Division – Board and Care Homes, Group Homes, Residential Treatment Facilities, Adult Foster Care	$43,138,066
Individuals served by the Addictions and Mental Health Division – Supported Housing	$839,460
Individuals served by the Addictions and Mental Health Division – In-Home Supports	$3,124,880

Oregon reported that, following the closure of its last ICF in 2009, virtually every person who qualifies for intellectual or developmental services is served in a community-based setting. The state also reported an expanded capacity to serve individuals with ID/DD. Specifically, the state spent $32.8 million to serve 6,693 individuals from 2006 to 2007 and spent $57.4 million to serve an estimated 7,661 individuals from 2012 to 2013. The state also increased supportive housing funding from $534,960 for 92 individuals in 2008 to $839,460 for 59 individuals in 2012.

Rhode Island

Rhode Island reported that, of the 3,590 individuals with ID/DD served by the state, 450 live in their own home or apartment, 1,419 live with their families, 224 live with a host family of their choosing, and

1,234 live in group homes in the community. The state also provided the following spending information:

Rhode Island Spending	
Setting	**State Dollars Appropriated to be Spent in State Fiscal Year 2013 (in millions)**
Rhode Island Community Living and Supports – Group Home System	$14.5
Community Provider Programs (Day Centers; In-Home services, etc.)	$91.3
Hospital, Psychiatric Care	$23.7

With regard to expansion, Rhode Island reported that, since it enacted its §1115 waiver in 2010, the state has added new services "to stimulate placement in the least restrictive community setting" and moved away from automatic group home placements. The state did not provide spending data for these programs.

Tennessee

Tennessee reported the following spending data:

Tennessee Spending	
Setting	**State Dollars Spent in State Fiscal Year 2012**
Nursing Homes	$321,183,900
HCBS for the Elderly and Physically Disabled	$53,244,800
ICF/IID	$57,837,500
HCBS for the Intellectually Disabled	$185,390,700
Supported Living Services in their own home for the Intellectually Disabled	$123,996,479.25

From 2008 to 2012, spending on HCBS remained approximately the same, and spending on institutions decreased. The number of individuals served in HCBS increased and in institutional settings decreased:

Tennessee Expansion in Capacity[a]				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$15,289,500	Not applicable	2,331	Not applicable
	Individuals Meeting ICF Level of Care			

Tennessee Expansion in Capacity[a]				
Program	**State Spending**		**Individuals Served**	
	2008	**2012**	**2008**	**2012**
	$201,070,500	$185,390,700	7,822	7,848
§1115 Waiver	Not applicable	$53,244,800	Not applicable	9,991
Other HCBS Programs	$5,330,500	$8,749,200	3,626	4,678
Nursing Facilities	$329,043,600	$321,183,900	23,089	21,203
Intermediate Care Facilities	$95,849,500	$57,837,500	1,215	1,072

[a] Tennessee had several waivers for individuals meeting the NF level of care, but in 2012, the state adopted an §1115 Waiver and shifted the NF level of care population to that waiver. Tennessee did maintain the three waivers for individuals meeting the ICF level of care. Since July 2012, Tennessee uses other programs to provide HCBS to individuals at risk of being placed in nursing facilities or intermediate care facilities.

Texas

Texas reported the following spending data:

Texas Spending	
Setting	**State Dollars Spent in Fiscal Year 2012 (in millions)**
Institutional – Nursing Facilities	$915,828,389
Institutional – Skilled Nursing Facilities	$64,042,149
Institutional – State Supported Living Centers - ICFs	$278,559,563
Institutional – ICF/ID	$121,767,235
Home-based – Home and Community-based Services Waiver, Residential	$170,297,413
Home-based – Home and Community-based Services Waiver, Non-Residential	$169,210,986
Home-based – Community-based Alternatives Waiver	$106,945,618
Home-based – Community Living Assistance and Support Services Waiver	$81,636,940
Home-based – Deaf Blind with Multiple Disabilities Waiver	$3,277,178
Home-based – Medically Dependent Children Program Waiver	$17,359,670
Home-based – Texas Home Living Waiver	$16,306,818
Home-based – PI services	$43,275,543

Texas Spending	
Setting	**State Dollars Spent in Fiscal Year 2012 (in millions)**
Home-based – Program of All-Inclusive Care for the Elderly	$14,855,838
Home-based – Primary Home Care	$128,451,821
Home-based – CAS	$205,596,805
Home-based – Day Activity & Health Services	$25,805,128
Home-based – STAR+PLUS Waiver	$558,492,232

From 2008 to 2012, spending on HCBS programs decreased and spending on institutions increased. The number of individuals served in HCBS increased and the number in institutional settings decreased.

Texas Expansion in Capacity				
Program	**State Spending**		**Individuals Served/Eligible**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$399,192,407	$280,680,801	40,415	51,366
	Individuals Meeting ICF Level of Care			
	$279,124,449	$443,087,098	18,609	28,747
Personal Care Services Option	$166,563,074	$126,550,932	51,569	30,125
Other HCBS Programs	$93,444,553	$39,569,857	12,860	4,481
	$84,305,866	$92,495,107	48,701	44,560
Nursing Facilities	$841,249,608	$982,847,339	62,592	63,142
Intermediate Care Facilities	$337,578,658	$391,832,337	11,177	9,499

Vermont

Vermont reported the following spending data:

Vermont Spending	
Setting	**State Dollars Spent in State Fiscal Year 2012**
Choices For Care Nursing Facility	$115,198,573
Choices For Care HCBS	$44,191,065

Vermont Spending	
Setting	**State Dollars Spent in State Fiscal Year 2012**
Choices For Care Enhanced Residential Care	$6,616,318
Assistive Community Care Services	$15,102,230
Support and Services at Home	$773,912
HomeShare	$142,545

From 2008 to 2012, spending on HCBS programs and on institutions decreased. The number of individuals served in HCBS and in institutional settings decreased, while the number of individuals served in assisted living facilities increased.

Washington

Washington reported the following spending information:

Washington Spending	
Setting	**State Dollars Spent in State Fiscal Year 2011–July 1, 2010 through June 30, 2011**
Nursing Homes	$205,635,000
ICF/ID-DD	$61,881,000
Group Homes	$7,876,000
Board and Care Homes	$36,710,000
Adult Family Homes	$55,518,000
Medicaid Personal Care, including all waiver personal care service	$314,732,00
State Psychiatric Hospitals	$211,093,816

From 2008 to 2012, spending on HCBS programs and on institutions increased. The number of individuals served in HCBS increased and the number in institutional settings decreased:

Washington Expansion in Capacity				
Program	**State Spending**		**Individuals Served/Eligible**	
	2008	**2012**	**2008**	**2012**
§1915(c) Waivers	Individuals Meeting Nursing Home Level of Care			
	$204,911,000	$188,791,000	31,246	35,977
	Individuals Meeting ICF Level of Care			
	$293,511,000	$326,847,000	9,510	11,666

Washington Expansion in Capacity				
Program	**State Spending**		**Individuals Served/Eligible**	
	2008	**2012**	**2008**	**2012**
Money Follows the Person	Individuals meeting the NF LOC			
	n/a	$8,330,000	n/a	1,294
	Individuals meeting the ICF LOC			
	n/a	$2,125,000	n/a	48
Personal Care Services Option	Individuals meeting NF LOC			
	$114,515,000	$171,184,000	17,913	20,390
	Individuals meeting ICF LOC			
	$53,131,000	$72,629,000	7,754	7,432
Nursing Facilities	$293,511,000	$326,847,000	19,462	18,776
Intermediate Care Facilities	$102,244,000	$90,260,000	1,268	1,151

West Virginia

West Virginia reported the following spending information:

West Virginia Spending	
Setting	**Estimated State Dollars to be Spent in State Fiscal Year 2013—July 1, 2012 to June 30, 2013 (in millions)**
Nursing Homes	$153
ICF	$18.6
Long-Term Care Units of Psychiatric Hospitals	$54.3
Psychiatric Hospitals	$65.9
Psychiatric Transitional Facility	$1.3
Supportive Housing	$5
Group Homes	$3.3

From 2010 to 2012, West Virginia reported a significant increase in spending on supportive housing: from $780,898 in 2010 to $4.6 million in 2012. The state also reported increased spending on its HCBS waivers and an increase in the number of individuals served by these waivers.

Wisconsin

Wisconsin reported spending 69 percent on HCBS and 31 percent on institution during state fiscal year 2011.

Wisconsin Spending	
Setting	**State Dollars Spent in State Fiscal Year**
Fee-for-service Institutions (NH, ICFs-MR, State Centers)	$882,659,229
MA Card Home Care	$259,953,133
Waivers (CIP, COP, BIW, Children, IRIS, MFP)	$285,798,043
Family Care	$1,267,176,236
PACE/Partnership	$194,304,493

Wisconsin reported that Medicaid spending on institutions has declined from 62 percent of LTSS expenditures in 2002 to 31 percent in 2011, while community-based expenditures have increased from 38 percent of LTSS spending to 69 percent. Further, the state reported that, in 2008, 93 percent of adult individuals with DD on Medicaid and 80 percent of adult individuals with physical disabilities on Medicaid were served in the community. By 2011, those figures had increased to 96 percent and 84 percent, respectively.

Wyoming

Wyoming reported the following spending information:

Wyoming Spending	
Setting	**State Dollars Spent in Fiscal Year 2012**
Nursing Facilities	$36,758,869
Skilled Nursing Facilities	$2,583,500
Assisted Living Facility Waiver Services	$1,833,927
In Home Services on Long-Term Care Waiver	$20,849,330
Community-Based In Home Services	$3,154,000
Wyoming Life Resource Center – ICF	$17,300,000
Residential Habilitation Services	$28,984,442
Supported Living Services	$2,878,423
All other DD/ABI waiver services supporting persons in their homes	$1,202,549
Self-Directed services through the waiver	$1,176,004

Wyoming Spending	
Setting	**State Dollars Spent in Fiscal Year 2012**
Wyoming State Psychiatric Hospital	$30,347,112
Therapeutic Living Environments	$3,988,434

From 2008 to 2011, Wyoming increased its spending on HCBS programs. The number of individuals served by HCBS programs also increased. For example, spending on the Assisted Living Facility Waiver, for individuals meeting the nursing home level of care, increased 7.4 percent, and the number of individuals served increased 8.1 percent.

Appendix 2: Highlights from States' *Olmstead* Plans

Alabama released its *Olmstead* plan in 2012. As of October 9, 2012, Alabama's planning efforts include operating seven HCBS waivers as part of its Medicaid program, including the Living at Home Waiver, the Independent Living Waiver, and the Community Transition Waiver. These waivers provide a range of services, including homemaker services, assistive technology, and skilled nursing. Alabama also noted that it recently closed its Partlow Developmental Center, the last state-run ICF for people with ID, and transitioned its 156 residents to community living. In addition, Alabama recently applied for MFP funding to assist significantly in transitioning more individuals to, and keeping them in, community settings. The state believes that this funding will also help those individuals to secure housing, in conjunction with resources from other federal, state, and local housing agencies. Further, Alabama recently became an "Employment First" state for its people with DDs by shifting from a focus on funding day programs and sheltered work to moving individuals into pre-vocational services as a prelude to attaining competitive employment. The state is also developing a §1915(i) state plan amendment to provide more HCBS for people with serious and persistent mental illness, which it intends to become operational in 2013.

Alaska did not provide information about *Olmstead* planning, but the state noted that all programs managed by its Department of Health and Social Services contemplate *Olmstead* implications.

Arizona issued its *Olmstead* plan in 2001, based on the following guiding principles: person-centered care management, consistency of services, available and accessible services, use of the most integrated setting, and collaboration with stakeholders. As of September 6, 2012, Arizona reported that its state Medicaid agency had met 11 of 14 goals identified in the plan and its Department of Economic Security/Division of Developmental Disabilities had met 13 of 16 goals. As part of its ongoing efforts, Arizona recently expressed its intent to participate in CFC. The state also completed an "extensive input-gathering series of community meetings to hear directly from providers, individuals, family members, and stakeholders and has allocated new funding for fiscal year 2013 to contractors based on the concepts developed with these groups, which prioritize integrated, peer-driven community based services."

Arkansas produced its *Olmstead* plan in 2003 according to the following key areas of need identified by the Governor's Integrated Services Taskforce: additional resources to support system improvements; increased community capacity; new approaches to service provision; and increased consumer-directed care. In 2008, the state reviewed its outlined goals and action steps to assess progress and identify remaining objectives. As a result, the state has "embarked on a broad health systems transformation initiative to support the health and well-being of all Arkansans, especially those with low household incomes and serious health conditions." A significant focus of this effort is the Arkansas Health Care Payment Improvement Initiative, which will bring together Medicaid and private insurance companies to design and build a new payment system that will drive the shift to a higher-quality and more cost-efficient system of care. Along with this effort, the state is pursuing several options to increase access to community-based services, including the CFC, the §1915(i) option, and the BIP program. In its September 12, 2012 response letter, Arkansas cited several achievements resulting from its *Olmstead* planning efforts, including the following:

- The MFP program successfully began transitioning adults out of skilled care facilities and into HCBS settings.

- A long-term care systems transformation grant enabled the state to establish the Choices in Living Aging and Disability Resource Center, which informally screens applicants for Medicaid eligibility and HCBS and helps them to initiate the formal application process.

- Wraparound services and supports, which allow children to remain in their home and communities, are available statewide to children with moderate to severe behavioral health needs and their families.

California released its *Olmstead* plan in May 2003 and later issued updates on implementation in 2005 and 2010. California's planning process included a series of local *Olmstead* forums hosted by stakeholders around the state to allow individuals to express their needs and preferences for living in the community and to share suggested best practices. The 2010 implementation update discusses four major categories of activity: state commitment, assessment and transition, diversion, and data and research.

- As evidence of its commitment to implementing *Olmstead*, California noted that, in 2005, it convened an *Olmstead* Advisory Committee to help inform policies and practices that impact Californians' abilities to receive services in the least restrictive environment and to avoid unnecessary institutionalization.

- With respect to financing LTSS, California noted that it has pursued every Medicaid program that Congress has approved that provides a tool to implement or expand HCBS, as well as pursued grants for demonstration and research projects. Along with many other examples listed in its November 14, 2012 response letter, California noted that its MFP Rebalancing Demonstration uses a tool that has both enabled the state to transition more than 900 individuals residing in NFs into the demonstration since December 2008 and educated many other individuals about their rights to informed choice.

- With respect to assessment, transition, and diversion, California's *Olmstead* plan includes goals to conduct timely assessments for persons in institutions to determine the supports and services needed for them to live successfully in the community. The plan also includes goals for timely assessments for persons living in the community who are at risk of placement in an institution, as well as goals for services that divert individuals at risk of institutionalization. For example, California's In-Home Supportive Services program serves more than 440,000 individuals in their homes, which, according to the state, makes it the largest personal care program in the country. This program increased the number of individuals served by more than 100 percent over a 10-year period.

- With respect to data and research, the California Medicaid Research Institute is currently analyzing individuals' experiences in avoiding long-term institutional placements through many home and community-based programs. The broad objectives of this project are to establish a robust database of 2005-2008 long-term care and HCBS data, analyze the use and impacts of HCBS and other long-term care services, and develop predictive modeling techniques that will inform California's HCBS policymakers.

Colorado is in the process of finalizing its *Olmstead* plan in response to an Executive Order issued by the Governor in 2009. Colorado's state Medicaid agency, the Health Care Policy and Financing Agency, is leading the development and implementation of the plan. The agency is working with a team of stakeholders, including people receiving services, case management and service providers, mental health professionals, home health providers, academics, state staff, and advocacy organizations, to develop recommendations and policy options. The *Olmstead* core team identified six key issues and

strategies to address each, including suitable financing, increasing housing options, expanding the current range of services, and better informing the community about services available for people with disabilities. In its September 6, 2012 response letter, Colorado noted that many of these recommendations have been incorporated as goals into the state's MFP grant. Colorado noted that, among other efforts, its state housing coalition has agreed to prioritize problem-solving barriers related to obtaining affordable and accessible housing for individuals who wish to transition into the community from institutional placement. Colorado has also revamped its nursing home admissions and review process to place a greater emphasis on transition potential and planning. In addition to operating 12 state HCBS waivers, Colorado is also exploring the feasibility of CFC.

Connecticut issued its *Olmstead* plan in 2002. According to its February 1, 2013 response letter, the state has further memorialized its commitment to increasing community integration in both a Long-Term Care Plan and a Strategic Rebalancing Plan. The Long-Term Care Planning Committee is charged with developing a long-term care plan for Connecticut every three years. The Long-Term Care Plan sets a goal to increase to 75 percent the incidence of individuals receiving community-based LTSS by 2025. Further, the Long-Term Care Plan makes 16 recommendations, including creating greater integration of state-level, long-term care administration and functions serving both older adults and people with disabilities and their families; simplifying Connecticut's Medicaid structure; and preserving and expanding affordable and accessible housing for older adults and individuals with disabilities. Further, the Strategic Rebalancing Plan incorporates goals, strategies, and metrics related to several areas, including connecting people to information about LTSS; creating parity across age and disability resources based on functional support needs, rather than diagnosis; increasing the availability of accessible housing and transportation; and transitioning 5,200 people from nursing homes to the community by 2016. Connecticut also notes that it has availed itself of many of the tools created by the federal government. For example, Connecticut's MFP initiative has transitioned more than 1,400 individuals from institutional settings to the community. In addition, Connecticut's Strategic Rebalancing Plan calls for conducting an impact analysis of the CFC Option. As evidence of its success in meeting goals for *Olmstead* implementation, Connecticut cites the shifting of LTSS and transitions of individuals through MFP. For example, the proportion of Medicaid clients receiving LTSS in the community has increased from 46 percent in state fiscal year 2003 to 56 percent in state fiscal year 2012.

Delaware issued in its *Olmstead* plan in 2008, in which it set 10 goals including ensuring a sufficient number of accessible housing options; implementing MFP; developing a consumer-driven health care system that would more effectively facilitate community living; and developing common assessment domains for eligibility and care planning. According to its September 14, 2012 response letter, the state's current priorities include creating a Speaker's Bureau that will educate the public on the ADA and *Olmstead* ruling; integrating financial empowerment services within the delivery system; and addressing the need for stronger data and quality assurance measures that promote choice, evidence-based practices, and payment for performance. In addition to its planning documents, Delaware provided copies of court monitor reports tracking the state's progress in reforming the state mental health system in response to a 2011 settlement agreement that resulted from *Olmstead* litigation. Pursuant to the agreement, Delaware undertook, along with other items, creating a comprehensive community crisis system to serve as the front door to the state's mental health system. Also pursuant to the agreement, Delaware committed to providing intensive community-based treatment and offering at least 650 housing vouchers or subsidies to allow people to obtain stable, integrated housing. According to the most recent court monitor report, Delaware "is largely meeting its benchmarks and it is making significant, sometimes ground-breaking, progress in retooling its systems in fulfillment of the ADA."

Hawaii adopted its *Olmstead* plan in 2005, after the Governor convened a task force of consumers, advocates, community agencies, and state staff to develop goals and strategies for implementation. In its September 19, 2012 response letter, Hawaii described the elements of its plan to increase community integration, such that each individual will be able to locate housing, acquire personal support personnel, use transportation, and engage in employment to sustain community-based living. Strategies to meet this goal include ensuring the availability of suitable housing, enabling people with disabilities to acquire the homes of their choice, and establishing and maintaining support service programs to assist people with disabilities to live in the homes of their choice. Hawaii has not incorporated the use of new federal tools into its plan, but the state notes that it has successfully implemented MFP, §1915(c) waivers, and PCS.

Illinois adopted the Disabilities Services Act to provide the foundation for a wider range of community-based services and supports and to establish a Governor-appointed advisory committee in 2003. According to the state's January 31, 2013 response letter, this committee was established to assist in the development and implementation of a Disabilities Services Plan. On September 29, 2010, Illinois entered into a consent decree to settle a class action *Olmstead* lawsuit. As part of the consent decree, Illinois was required to develop an implementation plan including the options offered for persons with serious mental illness to live in community-based settings. This plan, issued in 2011, provides information on topics including outreach and dissemination of information, housing, and transition to community-based settings. In 2009, the Governor's office created an Interagency Long Term Care Reform Team as a strategizing body focusing on the overall rebalancing agenda, implementation of an MFP demonstration, pursuit of the BIP program, and the then-pending consent decree. The state noted that the future of its service system across disability populations is guided by several overarching principles, including emphasizing and supporting choice, increasing system capacity for accessible, high-quality care, and supporting the network of persons with disabilities.

Iowa issued its initial *Olmstead* plan framework in 2010, after consultation with stakeholders, including advocates, policy-makers, and providers. The plan has five major goals for building the state's capacity to support all aspects of community integration: the creation of welcoming communities, increased access to integration and supports, a full offering of community-based services and supports, high-quality services and supports, and accountability for service results. According to its September 21, 2012 response letter, Iowa cites numerous accomplishments in furtherance of these goals, including the following:

- Iowa has reestablished its Office of Consumer Affairs (OCA), which is now fully staffed and operational with a statewide director, five regional coordinators, and five regional advisory committees. OCA serves as a statewide resource for information, referrals, community education, individual education, one-on-one problem-solving, and system navigation.

- Iowa ensured the availability of HCBS rent subsidies to support MFP participants and enrolled HCBS waiver members.

- Iowa enacted the Mental Health and Disability Services Redesign legislation, which in part requires implementation of standardized assessment tools for the ID/DD, mental illness, and brain injury populations.

- Iowa helped 188 individuals to transition from ICFs for persons with ID to more integrated community living settings through its MFP demonstration.

Kentucky issued its *Olmstead* plan in 2005. As part of its planning process, Kentucky created an *Olmstead* Consumer Advisory Council, which included more than 35 individuals representing various categories of disability, several geographic regions, and cultural diversity. The Council was responsible for advising Kentucky's Cabinet for Health Services on issues, concerns, and barriers for persons with disabilities, as well as enhancing the Cabinet's cultural sensitivity, diversity, and planning efforts throughout the long-term *Olmstead* compliance initiatives. In its September 13, 2012 response letter, Kentucky cites several accomplishments, including:

- Establishing the Aging Disability Resource Center (ADRC) network to provide consumers and families with meaningful information about choices that they can understand.
- Creating the Supports Intensity Scale, which assesses adults' support needs.
- Approving a plan to move all residents of a Specialized Personal Care Home program located on the grounds of a psychiatric hospital to permanent, community-based housing at "scattered sites" in the Louisville metropolitan area. After all residents have moved, the program will cease to operate as a licensed personal care home. Kentucky projected that this transition would be completed by June 30, 2013.
- Launching an *Olmstead* Housing Initiative. The initiative aims to identify or create appropriate community housing for individuals who are part of the *Olmstead* population.

Maryland issued its State Disabilities Plan in 2009 and has also established a state disabilities commission. Since 2008, LTSS stakeholders have met monthly to guide the state's MFP demonstration efforts and quarterly to evaluate options for reform through a long-term care reform workgroup including advocates, providers, and legislators. These stakeholders have aided the development of Maryland's operational protocol, which outlines the state's goals and efforts to expand access to community-based services. The state's efforts include enhanced outreach to institutional residents, options counseling on HCBS, and statewide implementation of aging and disability resource centers. According to its February 4, 2013 response letter, Maryland has consistently met its benchmarks related to shifting spending and increasing participation in community-based services. In addition to participation in the MFP demonstration, Maryland is participating in the BIP program, developing an application for CFC, exploring an application for the §1915(i) option, and evaluating health homes as an option for individuals with behavioral health support needs.

Massachusetts released its *Olmstead* plan in 2008 as a roadmap for improving community-based supports for elders and people with disabilities while building upon a strong policy framework and history of rebalancing efforts. The *Olmstead* Planning Committee, a diverse group of stakeholders, including consumers, providers, advocacy organizations, and state agency staff, developed the plan. The stakeholders recommended convening a Standing *Olmstead* Advisory Committee to discuss *Olmstead*-related priorities, review progress of the Community First *Olmstead* Plan, and propose solutions to implementation obstacles. The Advisory Committee, which met in the fall of 2010, focused its initial activities on the development of an MFP demonstration proposal and subsequent implementation of the demonstration. Stakeholders are actively assisting the Commonwealth to incorporate newly available rebalancing tools through the ACA. Massachusetts cites several initiatives in support of the plan's goals, including passing legislation for the development of up to 1,000 permanent supportive housing units, implementation of a nursing home closure plan, and operation of §1915(c) waivers.

Michigan convened a Medicaid Long-Term Care Task Force, due in part to *Olmstead* and the state's settlement in a subsequent lawsuit. The Task Force included individuals receiving services and/or their

family members, advocates, state agency staff, state legislators, and health care professionals. The Task Force recommended that the state implement person-centered planning practices monitored by various state agencies. The Task Force also recommended strengthening the state's offering of services and supports and expanding the range of options available to individuals. As a result, eligible individuals may be eligible for a variety of services and supports offered through several waiver programs. In 2005, Michigan created the Michigan Long-Term Care Supports and Services Advisory Commission, which includes individuals representing a broad spectrum of long-term care such as persons receiving services, advocates, direct care staff, trade organizations, and researchers. The Commission's duties include oversight of the implementation of the Task Force's recommendations and advising the state. In 2008, a workgroup composed of advocates, people receiving services, and multiple department staff developed a planning policy and guidelines. Further, in 2007, Michigan first received MFP funding. According to the state's September 19, 2012 response letter, Michigan recently submitted a proposal to CMS to integrate care for individuals eligible for Medicare and Medicaid. The state is also reviewing other options to improve efforts at community integration further, including CFC, the §1915(i) option, and the BIP program.

Minnesota, through its Department of Human Services, entered into a settlement agreement that requires the creation of an *Olmstead* plan as a result of *Olmstead* litigation in December 2011. According to the state's September 12, 2012, response letter, Minnesota's *Olmstead* Planning Committee includes individuals with disabilities, family members, providers, advocates, and state government staff. The committee identified six areas in which to make recommendations for action, including person-centered planning and community-based services and supports that enable people to live and work in the community. Pursuant to the settlement agreement, Minnesota projected that the plan would be fully implemented by June 2013.

Missouri implemented MFP, which completely replaced the state's previous *Olmstead* activities, in 2007. Missouri's initial goal was to transition 250 individuals from institutional settings between fiscal year 2008 and fiscal year 2011. According to its September 7, 2012, response, the state exceeded this goal by transitioning 276 individuals during that time. Subsequently, Missouri received an extension of its MFP grant through 2016. The state's new goals include transitioning 177 individuals during calendar year 2012; as of August 29, 2012, the state had transitioned 123 individuals. In addition, Missouri has partnered with the Aging and Disability Resource Center and the University of Missouri-Kansas City to develop curriculum to provide trainings to educate the community. Missouri plans to monitor these trainings for effectiveness and, once the demonstration is completed, conduct trainings statewide.

Nebraska, through its Division of Developmental Disabilities, implemented new regulations, which included several provisions that encourage individuals to live in their own homes, in July 2011. For example, the state's Division of Medicaid & Long-Term Care implemented MFP in June 2008. Nebraska has also enacted legislation that established a housing assistance program for individuals with serious mental illness. Further, according to the state's September 7, 2012 response letter, Nebraska renewed its two §1915(c) waivers for adults with DD to incorporate self-directed services in January 2010. As a result, individuals now have the flexibility to choose specialized (agency-based) or non-specialized (individual provider) services, or to mix those types of services. Because Nebraska does not have a waitlist for either waiver, clients who wish to move to a community setting are able to do so upon meeting the waiver criteria.

New Mexico has coordinated its efforts to increase community integration primarily through three state agencies, according to its September 2012 response letter to Chairman Harkin. Through these agencies, New Mexico has implemented §1915(c) waivers in its Coordination of Long-Term Services Program. The program's requirements include identifying eligible nursing home residents who wish to move from

institutions to home settings; offering relocations services; and providing transition services, including specialized medical equipment. New Mexico also cites its Mi Via program, which allows individuals to self-direct their own care by, among other things, hiring and retaining their own caregivers.

New York created an *Olmstead* Plan Development and Implementation Cabinet through the Governor's executive order on November 30, 2012. The Cabinet, composed of representatives of state agencies that provide services to persons with disabilities, is directed to make recommendations regarding:

- identification of the essential requirements of compliance with *Olmstead* and the ADA;
- assessment procedures to identify people with disabilities who could benefit from services in a more integrated setting;
- measurable progress goals for achieving integrated residential living, including transition goals from segregated to residential housing, and employment opportunities for people with disabilities; and
- measurable goals for providing supports and accommodations necessary for successful community living.

The expectation is that the Cabinet will develop a comprehensive strategy for meeting the obligations of the *Olmstead* decision. The executive order calls for a final report with recommendations for the establishment, implementation, and coordination of the *Olmstead* plan to the Governor in 2013.

Oregon issued its *Olmstead* plan in February 2011, after a yearlong planning process conducted by consumers, advocates, and state and local officials. The plan addresses five focus areas, including reducing state hospitalization, ensuring individuals get the residential services that they need, and increasing the availability and quality of commercial supports. The state has developed strategies for each focus area, such as implementing the §1915(i) option to improve the local community's ability to provide services to individuals in their own homes. In its September 6, 2012, response letter, Oregon noted that its Adult Mental Health Initiative, a comprehensive effort to provide incentives and accountability for providers to ensure that individuals are constantly moving toward independence, represents a key component of its plan. Further, the initiative requires local and regional contractors to engage actively with individuals. During the first 10 months of the initiative, 494 individuals successfully transitioned to lower levels of care. During the second phase, 440 individuals transitioned to lower levels of care.

Rhode Island did not address the issue of *Olmstead* planning, but the state did note several accomplishments furthering the creation of integrated settings for individuals with disabilities. These accomplishments include the closure of state-run institutions in the 1990s; placement of over 95 percent of individuals with ID/DD in community settings; and increasing additional options to maintain independence, such as transportation and job training opportunities.

South Dakota did not address the issue of *Olmstead* planning, but the state did note that its Department of Human Services' annual budget request has included the capacity to expand supports for individuals with disabilities, and that the state has no waiting lists for HCBS. South Dakota also noted that it uses four HCBS waivers to meet the demand for community living and that it recently received an MFP grant, which it hopes to use to afford individuals with disabilities additional options to transition to community living.

Tennessee has passed legislation and implemented reforms of its LTSS delivery system, which it intends promote the expansion of HCBS and rebalance expenditures. According to the state's February 1, 2013 response letter, the delivery system for qualifying individuals who need the level of care provided in an ICF/ID includes three §1915(c) waivers, which served a combined total of 7,686 individuals as of November 2012. One of the programs, the Self-Determination Waiver, permits self-direction of selected services, including personal assistance. The waivers also include community-based residential alternatives to institutional placement. Stakeholders, including an advisory council, have been actively involved in the development of these programs. In addition, Tennessee's current HCBS alternative to NF level of care is the TennCare CHOICES in Long-Term Services and Supports Program (or CHOICES), which serves both adults age 65 and older and adults age 21 and older with physical disabilities. The CHOICES program originated as the result of comprehensive long-term care reform legislation passed unanimously by both houses of the Tennessee General Assembly in 2008. As of February 1, 2013, 20,237 persons were receiving Medicaid-reimbursed NF services in just fewer than 300 licensed and certified NFs statewide, and 12,104 persons were receiving HCBS as an alternative to NFs. Since the implementation of the CHOICES program in 2010, the percentage of persons enrolled in HCBS (as opposed to NFs) has increased by 120 percent. During the same period, the number of individuals enrolled in HCBS increased by nearly 150 percent and the number of persons enrolled in NFs has decreased by more than 12 percent.

Texas did not specifically address its *Olmstead* plan as part of its response. However, the state issued a plan in 2001, with a fifth revision released in 2010 based on guidance from the state's Promoting Independence Advisory Committee.

Vermont did not specifically address its *Olmstead* plan as part of its response. However, the state released a plan in 2006 under the guidance of the state's *Olmstead* Commission, a group of individuals representing consumers, family members, state government, advocacy organizations, and providers, created by the Vermont legislature in 2002.

Virginia issued a restructured *Olmstead* plan in July, 2012, divided into three main categories: community living supports, housing, and employment and community engagement. The report includes recommendations pertaining to each issue, such as exploring other HCBS options outside of §1915(c) waivers; educating state and local governments, individuals, families, and communities about available housing options; and reinvesting profits from state institution land sales into community housing options and other community supports. Further, in July 2012, the Commonwealth issued a report addressing Virginia's progress in meeting the benchmarks of a settlement agreement resulting from DOJ's findings against the Commonwealth for non- compliance with the ADA. In part, the agreement requires the Commonwealth to provide community-based services through Medicaid waivers and family supports for more than 5,000 individuals with ID/DD who are unnecessarily institutionalized, either in Virginia's five state-operated Training Centers, or in state-funded private facilities, and for individuals who are at risk of unnecessary institutionalization because of a lack of adequate community supports and services. To date, the Governor has placed a "down payment" of 30 million dollars in the Commonwealth's budget specifically for transitioning people currently living in institutions and nursing homes to community living situations.

Washington updated its *Olmstead* plan in 2005, and, according to its September 16, 2012 response letter, has since added activities associated with MFP, Real Choices, and Roads to Community Living federal grants to improve the state's capacity to help people either avoid institutionalization or return to their home communities. The state noted that it has transitioned more than 1,800 individuals from institutions through its MFP demonstration program, thus far exceeding its original projections.

West Virginia established the *Olmstead* Coordinator's Office on August 13, 2003, which it charged with developing, implementing, and monitoring West Virginia's *Olmstead* activities in compliance with the ADA. Also in 2003, West Virginia established the *Olmstead* Advisory Council as the steering committee for the development of an *Olmstead* plan. The Council decided to finalize West Virginia's plan as a result of DOJ's July 2011 guidance on *Olmstead* enforcement, and it later held statewide public forums and targeted focus groups in June and July 2012. According to the state's August 30, 2012 response letter, the plan addresses 10 major components of *Olmstead* compliance: informed choice, identification, transition, diversion, reasonable pace, eliminating institutional bias, self-direction, rights protection, quality, and community-based supports. Upon completion of the draft plan, the Council will release it for a 30-day public comment period. The Council's goal is to complete the plan in 2013. West Virginia also noted that it has used federal tools to help it meet its obligations under the ADA and *Olmstead*. For example, the state used federal Cash and Counseling grants to develop self-directed options for its Aged and Disabled Waiver Program. The state has also implemented a transition and diversion program that supports people to transition (or be diverted) from institution. Since 2008, the program has assisted 492 people to transition (or be diverted) for an average cost of $1,849 in start-up costs per person.

Wisconsin did not specifically address its *Olmstead* plan as part of its response. However, the state released a plan in 2002 after convening an advisory council to review the federal requirements of the ADA, as interpreted by the Supreme Court in *Olmstead*.

Wyoming issued its *Olmstead* plan in 2002 and is currently revising the plan, based on the state's planned redesign of its Medicaid waiver, and community mental health systems. As part of its redesign effort, the state is evaluating the current role of state-operated facilities and considering options to downsize some of its facilities. According to the state's September 13, 2012 response letter, the goals of these redesigns are to support people in the least restrictive setting, increase the capacity of local communities to support people with disabilities, provide services to more Wyoming citizens in need, and ensure that the state has a safety net system in place. These redesigns may later include plans to use the §1915(i) state plan amendment. Wyoming also noted that, in 2008, it initiated a project to facilitate seamless transitions for the admission/discharge process between hospitals and communities.

Appendix 3: States' Suggestions for Effective *Olmstead* Implementation

The states offered many suggestions and strategies for *Olmstead* Implementation, with the most common focused on the following broad categories: stakeholder involvement and collaboration, aging and disability resource centers, employment issues, housing and rental subsidies, and funding and financial incentives. The states also reported on suggestions for improving existing federal tools, including MFP, CFC, and BIP.

Stakeholder Involvement and Collaboration

Arizona convened a sustainability workgroup composed of people with disabilities, family members, advocates, service providers, and state personnel. This strategy of convening interested stakeholders has proven to be highly effective.

Arkansas noted that it has been most effective to develop task forces to assess the needs of individuals with disabilities across systems. This approach has been successful in supporting a broad analysis of needs and gaps in the state's current system. Stakeholder engagement has been a vital part of the Arkansas effort to transform the health care system by involving interested parties in each phase, including needs assessment, program design, program implementation, and program evaluation.

Iowa commented that engaging key stakeholders, especially persons with disabilities and their families, friends, and advocates, has been instrumental in moving toward community integration—"a life in the community for everyone." The opportunity to present and discuss multiple viewpoints and for stakeholders to work to find consensus together has enabled Iowa to make significant progress. In addition, Iowa highlighted its collaboration with private providers and noted that its *Olmstead* Consumer Task Force brings together individuals with disabilities, advocates, and representatives of 20 of Iowa's state departments and agencies to identify and recommend ways to overcome barriers to community living for people with disabilities.

Maryland cited its efforts in multi-agency collaboration and use of peer support models. The use of peers (i.e., people with disabilities and older adults) who have successfully lived in the community can help others to navigate the system and overcome obstacles. Peer support builds on the strengths and success of real-life experiences to address individual and family concerns about choosing the community as an alternative to an institution.

Massachusetts involved stakeholders in all aspects of planning for and implementation of its *Olmstead* initiatives. The Commonwealth's experience in creating its *Olmstead* plan exemplifies how engaged stakeholders can add valuable perspective to create a better product. In particular, Massachusetts cited stakeholder involvement in decreasing the number of ICFs and developing the "Duals Demonstration" to integrate Medicare and Medicaid.

Minnesota noted that it has a strong and active disability stakeholder community. Its Department of Human Services works extensively with other state agencies, community organizations, service providers, advocates, consumers, and the legislature to develop policy recommendations and implement programs. By bringing stakeholders together, the state designs and analyzes policies from multiple perspectives. This community approach helps Minnesota plan for changes to enhance community living more effectively.

Aging and Disability Resource Centers (ADRCs)

Several states advocate continued and/or enhanced support for ADRCs, which provide information on all aspects of life related to aging or living with a disability.

California suggested establishing a dedicated funding stream to facilitate expansion of ADRCs. Maintaining California's Aging and Disability Resource Connection partnerships over time without an ongoing revenue source has been and will continue to be problematic. In light of the current economic climate in California and state budget reductions, organizations have been stretched to perform their core functions.

Iowa noted that use of the ADRC model requires strong local partnerships to become fully functional. Strengthening centers for independent living and providing support for health care entities to partner with ADRCs will ensure that consumers have genuine "no wrong door" access to LTSS that meets the promise of *Olmstead*. Improving options for counseling services through ADRCs will promote ADRC sustainability.

Maryland, Minnesota, and West Virginia all cited successful use of ADRCs. For example, Maryland advocated continued support of ADRCs as a means to streamline eligibility determination for LTSS. Maryland noted that, through MFP and ADRC grants, it has developed collaborations between several state government agencies that offer services and supports for individuals with long-term support needs. These partnerships have resulted in a stronger ADRC program with a "no wrong door approach" to enhancing access to supports. Minnesota used its ADRC funds to establish www.minnesotahelp.info, a website designed to give all Minnesotans access to information about the services and supports available in their communities. Also part of this network are the Disability Linkage Line and Senior LinkAge Line®, two toll-free assistance lines that provide information and assistance with community resources to seniors and people with disabilities. Finally, West Virginia noted that its ADRCs play an integral role in its MFP program by helping to identify potential participants for grants and outreach.

Employment Issues

Iowa suggested that federal incentives for private sector employers to hire more individuals with disabilities may assist in promoting this important issue on a national scale.

Minnesota suggested establishing consistent policies on employment supports. The state noted that, in September 2011, CMS issued a bulletin to clarify existing CMS policies on employment supports under the §1915(c) Medicaid waiver programs. Although this guidance provided new insights into Medicaid options available to states, inconsistencies in definitions and principles of employment supports remain across federal funding streams. Medicaid, vocational services provided under the Rehabilitation Act of 1973, and the Individuals with Disabilities Education Act (IDEA), all support people with disabilities in their employment goals. Consistent policies for employment supports across these funding streams, including definitions of community-based and segregated employment, would make it easier for states to coordinate employment efforts to ensure that community-based employment is the preferred outcome.

Minnesota and Washington both commented that federal eligibility criteria for disability programs should not continue to be based on an individual's inability to work. Minnesota stated that community-based employment will not become an expectation for people with disabilities receiving public assistance if eligibility criteria act as a disincentive for enrollees to earn money. According to the state, changing the federal disability determination process to move away from using work history as criteria for eligibility would make it easier for states to support employment programs. Washington noted that

employment is one of the most effective ways to help people who rely on human services to avoid crisis, homelessness, and reduced capacity. Yet federal rules require people that apply for benefits because of disability to prove that they are "unable to work at a substantial gainful activity level." In addition, current federal rules governing the provision of behavioral health services require that authorization of supported employment fit into the medical/clinical model that governs the rest of the services delivered. Washington further stated that it would be useful for states to have additional funding streams for employment that encouraged implementation of evidence-based and promising employment practices for working-age people with disabilities, including supported employment. According to the state, such practices would result in employment at a living wage, which could be confirmed through reports from the state's unemployment insurance (UI) system. Also according to the state, even better would be funding streams that reward success with a percentage of the UI earnings of target workers that states could reinvest in employment support infrastructure and technical assistance.

Michigan enacted the Ticket to Work and Work Incentives Act of 1999, and under this act, implemented a Freedom to Work/Medicaid Buy-in program in January 2004. Enrollment has grown from less than 300 in early 2006 to more than 7,000 individuals in 2012. As a result, individuals are earning more money and paying more of their medical costs. This program also led to the development of an interagency agreement to increase employment opportunities for persons with disabilities in 2009.

Wyoming convened a state Integrated Employment Team to begin developing a strategic plan for increasing employment outcomes for people with DD in 2012. The Team's goals are to collaborate with other state agencies and stakeholders to research and support best practices in supported employment, build partnerships, and develop realistic transition plans to move people into competitive employment. The state anticipates that, as a result, there will be more people in its programs who are working and making livable wages, who will also want to live more independently, build and rely on natural supports, have a greater quality of life, and have less dependence on government programs and assistance.

Housing and Rental Subsidies

Alabama noted that its Department of Mental Health partnered with the Alabama Housing Finance Authority to utilize HUD funds and Low Income Housing Tax Credits to fund set-asides of up to 15 percent of units of housing built for people with mental disabilities. This strategy has enabled hundreds of individuals to live independently.

Arizona cited its Bridge Subsidy Program, which provides tenant-based permanent supportive housing vouchers for individuals with serious mental illness. The initiative provides individuals with more housing choices and the flexibility to select a unit and neighborhood that meets their needs and preferences. The program was designed as a bridge to help individuals access HUD housing vouchers eventually.

California and New Mexico advocted increasing federal incentives for housing. According to the states, strong partnerships between health and LTSS providers with affordable housing developers are necessary to implement ADA provisions effectively. Also according to the states, federal incentives for housing developers to create housing for low-income seniors and persons with disabilities, with requirements to partner with health and LTSS providers, would result in more supportive living environments. New Mexico commented that, to keep an individual in the community, there must be adequate housing and transportation. Many individuals need specialized housing and other environmental modifications, such as larger doorways, ramps, and grab bars. As a result, communities that lack appropriate housing incur conversion costs.

Colorado and Minnesota suggested increasing access to HUD housing vouchers and other subsidized housing options for people with disabilties. In particular, Minnesota commented that, due to the long waiting lists for housing assistance, many people apply for vouchers at several public housing authorities in an effort to access assistance sooner. However, there are often varying applications and procedures to apply for assistance at each authority. Consequently, according to the state, a streamlined application process across public housing authorities would enable people with disabilities to receive housing assistance sooner.

Colorado also said that its Department of Housing partners with more than 50 community-based service providers and public housing authorities and thousands of private landlords to combine housing assistance with supportive services. These providers include mental health centers, centers for independent living, community center boards, and homeless service providers. According to the state, the four-way partnership between the department, the service agency, the property owner, and the participant is an effective and efficient approach to providing housing and supportive services to more than 5,000 Colorado residents.

Connecticut recommended additional flexibility with HUD institutional underwriting. According to the state, HUD should explore moving the nursing home asset from the institutional portfolio to the housing portfolio, so that nursing home space can be converted to housing.

Delaware suggested updating HUD programs to direct more funding to support the population of individuals with disabilities. According to the state, access to affordable housing remains a critical component of community integration, and congregate living was created largely in response to fiscal reality and affordability concerns. The state noted that Medicaid provides payment to LTC facilities for room and board but does not support rental costs within a community-based setting.

Illinois suggested that Local Housing Authorities should open waiting lists to accept applications from individuals who have lived in institutional settings and who either have not been afforded opportunities to apply for Housing Choice Vouchers or who may have not responded to letters due to their mental illness.

Maryland advocated continued collaboration between CMS and HUD to expand affordable housing options for people in need of long-term support. The state noted that, through this partnership, HUD could designate funding for the rehabilitation of vacant housing stock to create more affordable and accessible housing options to support transitions from institutional settings, issue additional vouchers, and allow nonprofit organizations to access vouchers if the applicable public housing authority chooses not to seek the new vouchers.

Minnesota provides subsidy funding to supportive housing projects to fund a range of supports and non-reimbursable services that are vital for persons with serious mental illness to obtain and retain affordable rental housing. Supports vary by housing project but include tenant service coordination, front desk cost, security, and gap financing for rent stabilization for persons with very low income.

Funding Issues and Federal Financial Incentives

California provided several suggestions related to funding and financial incentives, including the following:

- Expanding the federal financial participation for HCBS: Current Medicaid eligibility determination of federal-state sharing of LTSS favors institutional placement. Families

should be supported to care for their loved ones in the community with Medicaid HCBS, as opposed to obtaining Medicaid-covered institutional services. Higher federal financial participation for all HCBS would enable states to provide more community-based services, rather than receiving the same federal financial participation for institutional services. The CFC Option is an encouraging step in the right direction, but it should be expanded to include all home and community-based Medicaid services, as opposed to being limited to self-directed, personal, and attendant services.

- Removing state match requirements for new federal assistance: Given state budget realities, California recommends that any new federal assistance not require state match or state sustainability requirements that would be so potentially financially difficult that states with budget constraints cannot participate.

- Providing funding for nursing home referrals.

Kentucky suggested reinstating the increased FMAP and having a higher federal match for community-based psychosocial treatments and interventions to incentivize community-based services instead of inpatient institutional services. The Commonwealth also suggested eliminating the requirement for budget neutrality for community waiver programs

Maryland recommended incentivizing diversion from institutions, as the MFP demonstration incentivized transition out of institutions. According to the state, diversion incentive programs would reduce institutionalization for individuals currently eligible for community Medicaid and eliminate the barriers to community living caused by the institutional stay, such as loss of housing and learned dependence.

Minnesota suggested enhancing options to provide family/caregiver supports. According to the state, people with disabilities who are served by public programs are often also served informally by caregivers and family members without reimbursement. These individuals allow people with disabilities to be supported in their communities by caregivers of their own choosing. As the baby boomer generation ages into disability and people with disabilities live longer, reliance on formal supports will grow. Enhancements in the federal options to provide support to caregivers, regardless of the level of need of the person being served, would help to retain the informal supports that maintain people in the community. The state also suggested that provision of quality long-term care services to people with disabilities is critical to providing a functional, safe, and effective service system. However, quality activities, such as monitoring and assurance, can be prioritized after service provision in difficult economic conditions. Similarly, quality standards may be developed but not fully enforceable without dedicated resources. Also according to the state, a specific reimbursement methodology for quality improvement activities across funding streams would allow Minnesota and other states to implement comprehensive quality assurance measures.

New Mexico provided a variety of suggestions related to funding and financial incentives, including noting inadequate reimbursement for many service providers. New Mexico advocated for more flexibility to provide adequate services to urban, rural, and frontier areas. According to the state, establishing block grants that permit the state to serve its population would be more appropriate than simply increasing Medicaid funding because (1) while Medicaid serves approximately one in four New Mexicans, it does not cover many individuals that need assistance to remain (or be diverted) in the community and (2) the special needs of this population cross various agencies that require specific coordination.

Tennessee expressed concern about implementation of proposed rules regarding expansion of fair labor protections to domestic workers providing certain types of HCBS. The state believes these rules will have a significant negative impact on its abilities to comply with the *Olmstead* decision. If states are forced to pay higher rates for these services, the result will be reductions in the numbers of people that can be served or the amount of services that can be provided, as states simply do not have an unlimited supply of resources. More people will be forced into expensive institutional settings because care at home is no longer affordable, placing states at significant risk of litigation regarding the Americans with Disabilities Act—not because they have reduced their funding for home and community based care, but rather, because these regulations will require that more of a state's limited resources are required in order to provide a lesser amount of home-based care.

Washington commented that the FMAP rate is the same for institutional programs and for community-based programs. According to the state, if community-based services are preferred, an improved FMAP rate for community-based services that are "truly integrated settings" where people are "living in their own homes, engaged with family, friends[,] and their communities" would encourage states and provide resources needed to develop these settings further.

Community First Choice

Alaska commented that removing the institutional level of care requirement from CFC would be an excellent strategy to remove barriers to integration for individuals who have functional limitations but do not require hands-on nursing assistance.

Kentucky suggested expanding CFC to include all community services (i.e., supported employment, community integration, etc.) to create a "supermarket" of services for people based on functional need rather than diagnosis.

Tennessee commented that CFC requires that states make attendant care services available statewide, with no caps on the number of people who can receive the benefit and no ability to target the benefit based on age, or severity of disability. According to Tennessee, this has discouraged many states from participating in the program. Also according to the state, this lack of flexibility to manage the program within each state's budgetary constraints and ensure an adequate community infrastructure to deliver the benefits will likely continue to impact the numbers of states electing to pursue these options.

Washington has implemented a robust, community-based service system over the last 30 years, according to the state. Washington characterizes the latest congressional efforts to encourage states to develop community-based services and avoid institutionalization as not being especially helpful to the state, since it spends 76 percent of its current funding on HCBS and 24 percent on institution-based systems of care. Washington is, however, evaluating whether or not options offered in CFC and the §1915(i) option may be helpful to continuing the work being done to ensure that people may remain in their home communities. Washington thinks that it would be helpful if Congress recognized those states that have already done much to rebalance their systems with additional federal support, rather than only using additional federal support to encourage states who have done little in that regard. For example, Congress could allow high-performing states to claim more FMAP for community-based services than they claim for institutional services.

Balancing Incentive Payment Program

California noted that, because of its rebalancing achievements to date, it is not eligible for BIP, which includes the benefit of an enhanced federal match for services. California suggests allowing states that

took early action to be compliant with the *Olmstead* decision to qualify for Medicaid incentive payments when more than 50 percent of their LTSS expenditures are in community-based settings, rather than institutions.

Colorado noted that it is not eligible for BIP because the state's investments in HCBS exceed the eligibility threshold for the program. The state commented that the program is a great opportunity that encourages states to create a more customer-friendly entry point system for LTSS, establish a conflict-free case management system, and develop a universal assesment for LTSS eligibility and service planning. According to the state, many states, includig Colorado, need to do this fundamental work, to create more responsive, person-centered LTSS systems that provide services in the most appropriate settings based on the clients' choices and needs. Because changing these entrenched systems will be a political, lengthy process, Colorado suggested that the federal government should consider creating more opportunities to encourage states to change their systems.

Hawaii commented that it is relatively disadvantaged with regard to the new federal assistance. According to the state, the new federal assistance appears to incentivize states that do not have robust HCBS programs and is not as beneficial to states like Hawaii that have already enacted such programs.

Tennesee reccommends allowing state spending on LTSS to be calculated by LTSS population. As it is currently applied, only one state qualifies for the five percent enhanced FMAP because spending is combined across populations served by each state in their LTSS programs. According to the state, a two percent match is often not substantial enough to offset the significant administrative burden that will be required to achieve program requirements. Also according to Tennessee, in nearly every state, spending on persons with ID/DD is overwhelmingly balanced in favor of HCBS. This is not true for the elderly and adults with physical disabilities. Separate consideration of funding for different LTSS populations would allow more states to qualify for the five percent FMAP and increase the likelihood that states will elect to participate in the program to assist their rebalancing efforts.

Endnotes

[1] A 2012 article in *Research and Practice for Persons with Severe Disabilities* summarized the results of 36 high-quality studies comparing changes in general daily living skills of individuals with developmental disabilities before and after leaving institutions for community living either for individuals themselves or in comparisons of matched groups of people who moved and those who stayed behind. Thirty-one of those 36 studies (86%) showed better results for those moving to lives in the community associated. Similarly, in 20 analyses of skills development in specific domains of academic, community living, language/communication, motor/physical, self-care/domestic, vocational and social skills, 85% of 75 comparisons made showed benefits of moving from institutions to community settings. In reality very rarely are social policies supported with such strong and consistent evidence their benefits. Larson, S., Lakin, K.C., & Hill, S., *Behavioral outcomes of moving from institutional to community living for people with intellectual and developmental disabilities: U.S. studies from 1997 to 2010*, 37 RESEARCH AND PRACTICE FOR PERSONS WITH SEVERE DISABILITIES, 235 (2012).

[2] The advocacy group ADAPT notes that there are over 2 million people with disabilities of all ages in nursing homes and other institutions and over 250,000 people in nursing homes want to return to the community, http://www.adapt.org/housing. See also NAT'L COUNCIL ON DISABILITY, INCLUSIVE LIVABLE COMMUNITIES FOR PEOPLE WITH PSYCHIATRIC DISABILITIES (2008) available at http://www.ncd.gov/publications/2008/03172008 (26 studies on consumer preferences in housing found that approximately 60 percent of survey respondents preferred to live in integrated housing, either alone or with a spouse or partner, and did not want to live primarily with other people with psychiatric diagnoses).

[3] We use the term long-term services and supports rather than long-term care. Long-term services and supports is a term that is commonly used by researchers and policymakers to describe the types of assistance that are provided to persons with disability and frail, elderly individuals. The Patient Protection and Affordable Care Act uses the term long-term services and supports and defines the term to include certain institutionally based and non-institutionally based long-term services and supports. Pub. L. No. 111-148, §10202(f)(1), 124 Stat. 119, 926-27 (Mar. 23, 2010).

[4] 42 U.S.C. §1396d(a)(24).

[5] 42 U.S.C. §1396d(a)(13).

[6] Assertive community treatment provides comprehensive services in the community through an interdisciplinary team. Services are furnished in a flexible manner in accordance with the needs of the individual, and can be 24 hours a day, seven days a week. Intensive case management programs provide individualized, community-based services that assist individuals with housing, employment, social relationships, and community participation. Mobile crisis services can reduce clinical risk, serve individuals in the community, and reduce over-reliance on hospitals and facility-based services. Peer support services are provided by self-identified consumers who are in recovery from mental illness and/or substance use disorders and provide counseling and care coordination, in addition to other support services.

[7] 42 U.S.C. 1396n(g)(2).

[8] 42 CFR 440.169.

[9] 42 CFR 440.169(b).

[10] U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-10-801, MEDICAID MANAGED CARE CMS'S OVERSIGHT OF STATES' RATE SETTING NEEDS IMPROVEMENT (2010).

[11] PAUL SAUCIER ET AT., The Growth of Managed Long-Term Services and Supports (MLTSS) Programs: A 2012 Update (2012), *available at* http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Downloads/MLTSSP_White_paper_combined.pdf.

[12] Kaiser Commission on Medicaid and the Uninsured, Examining Medicaid Managed Long-term Service and Support Programs: Key Issues to Consider (Washington, D.C.: October 2011).

[13] 42 U.S.C. §12101 (2009).

[14] *Id*.

[15] 42 U.S.C. §12132.

[16] 28 C.F.R. §35.130(d).

[17] *Olmstead*, 57 U.S. 581.

[18] *Id*. at 583.

[19] *Id*.

[20] *Id*. at 601.

[21] *See*, Statement of the Dep't of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead* v. L.C., *available at* http://www.ada.gov/Olmstead/q&a_Olmstead.htm.

[22] Organizations that espouse these principles are ADAPT, American Association of People with Disabilities, American Diabetes Association, Association of University Centers on Disabilities, The Arc of the United States, Autistic Self-Advocacy Network, Bazelon Center for Mental Health Law, Depression and Bipolar Support Alliance, Disability Rights Education and Defense Fund, Little People of America, Mental Health America, National Alliance on Mental Illness, National Association of Rights Protection and Advocacy, National Association of State Directors of Developmental Disabilities Services, National Association of State Mental Health Program Directors, National Coalition for Mental Health Recovery, National Council for Community Behavioral Healthcare, National Council on Independent Living, National Disability Rights Network, National Federation of the Blind, the National Mental Health Consumers' Self-Help Clearinghouse, National Organization on Disability, Paralyzed Veterans of America, TASH, and United Spinal Association.

[23] *See, e.g.*, Fisher v. Oklahoma Health Care Auth., 335 F. 3d 1175 (10th Cir. 2003); Townsend v. Quasim, 328 F.3d 511 (9th Cir. 2003); Radaszewski ex. rel. Radaszewski v. Maram, 383 F.3d 599, 609 (7th Cir. 2004).

[24] *Id.*

[25] EMILY C. BARBOUR, CONGRESSIONAL RESEARCH SERVICE, CRS-7-5700, *OLMSTEAD V. L.C.:* JUDICIAL AND LEGISLATIVE DEVELOPMENTS IN THE LAW OF DEINSTITUTIONALIZATION (NOV. 2011).

[26] *See*, The Arc of Washington State, Inc. v. Braddock, 427 F.3d 615 (9th Cir. 2005);

Sanchez v. Johnson, 416 F.3d 1051 (9th Cir. 2005).

[27] Olmstead *Enforcement Update: Using the ADA to Promote Community Integration Before the S. Comm. On Health, Education, Labor, and Pensions*, (2012)(statement of Thomas E. Perez, Assistant Attorney General, Civil Rights Division, Dep't of Justice), *available at* http://www.justice.gov/crt/opa/pr/speeches/2012/crt-speech-120621.html.

[28] *Id*.

[29] Participation by the United States in Olmstead Cases, DEP'T OF JUSTICE, (last visited June 3, 2013) http://www.ada.gov/Olmstead/Olmstead_cases_list2.htm#NC.

[30] Olmstead *Enforcement Update: Using the ADA to Promote Community Integration Before the S. Comm. On Health, Education, Labor, and Pensions*, (2012) (statement of Thomas E. Perez, Assistant Attorney General, Civil Rights Division, Dep't of Justice), *available at* http://www.justice.gov/crt/opa/pr/speeches/2012/crt-speech-120621.html.

[31] Serving People with Disabilities in the Most Integrated Setting: Community Living and Olmstead, U.S. DEP'T OF HEALTH AND HUMAN SERVICE, http://www.hhs.gov/ocr/civilrights/understanding/disability/serviceOlmstead/ (last visited June 3, 2013).

[32] *Id*.

[33] CYNTHIA H. WOODCOCK, HILLTOP INSTITUTE AND NATIONAL GOVERNORS ASSOCIATION, LONG-TERM SERVICES AND SUPPORTS: CHALLENGES AND OPPORTUNITIES FOR STATES IN DIFFICULT BUDGET TIMES (2011), *available at* http://www.hilltopinstitute.org/publications/LTSSChallengesandOpportunitiesforStatesindifficultBudgetTimes-December2011.pdf.

[34] U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-649, MEDICAID STATES' PLANS TO PURSUE NEW AND REVISED OPTIONS FOR HOME- AND COMMUNITY-BASED SERVICES (2012).

[35] Kaiser Commission on Medicaid and the Uninsured, Medicaid Home- and Community-Based Services Programs: 2009 Data Update (Washington, D.C.: December 2012).

[36] WOODCOCK ET. AL, THE HILLTOP INSTITUTE, UMBC, REBALANCING LONG-TERM SERVICES AND SUPPORTS: PROGRESS TO DATE AND A RESEARCH AGENDA FOR THE FUTURE (2011), *available at* http://www.hcbs.org/files/208/10361/RebalancingLTSS-ProgressToDateAndResearchAgendaForFuture-June2011.pdf.

[37] STEVE EIKEN ET AL., MEDICAID EXPENDITURES FOR LONG-TERM SERVICES AND SUPPORTS: 2011 UPDATE, (2011).

[38] CHARLENE HARRINGTON ET. AL, HOME AND COMMUNITY-BASED SERVICES: PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY (2009) *available at* http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.php.

[39] UNITED CEREBRAL PALSY, THE CASE FOR INCLUSION (2013), *available at* http://www.ucp.org/the-case-for-inclusion/2013/images/Case_For_Inclusion_Report_2013.pdf.

[40] Terence Ng et al., *Medicare and Medicaid in Long-Term Care*, 29 HEALTH AFF. 1 (2010)(citing Ng T, Harrington C, O'Malley M. Unpublished data update for Medicaid home and community based service programs. Washington (DC): Kaiser Commission on Medicaid and the Uninsured; 2009.

[41] CHARLENE HARRINGTON ET. AL, HOME AND COMMUNITY-BASED SERVICES: PUBLIC POLICIES TO IMPROVE ACCESS, COSTS, AND QUALITY (2009) *available at* http://www.pascenter.org/documents/PASCenter_HCBS_policy_brief.php.

[42] *Id.*

[43] Grabowski et al., *Mental Illness in Nursing Homes: Variations Across States*, HEALTH AFFAIRS, May/

June 2009, at 689.

[44] NATIONAL COUNCIL ON DISABILITY, OLMSTEAD: RECLAIMING INSTITUTIONALIZED LIVES (August 2003), *available at* http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm

[45] Joseph Shapiro, *A New Civil Right Looks for Stronger Enforcement*, NPR (June 18, 2013), http://www.npr.org/2010/12/03/131786390/a-new-civil-right-lacks-enforcement.

[46] THE BAZELON CENTER, STILL WAITING…THE UNFULFILLED PROMISE OF OLMSTEAD (2009), *available at* http://www.bazelon.org/LinkClick.aspx?fileticket=S5nUuNhJSoM%3d&tabid=10.4.

[47] Kaiser Commission on Medicaid and the Uninsured, Medicaid Home- and Community-Based Services Programs: 2009 Data Update (Washington, D.C.: December 2012).

[48] See Mitchell P. LaPlante, *The Woodwork Effect in Medicaid Long-Term Services and Supports*, 25 J. of Aging & Soc. Pol'y. 161 (2013).

[49] Stephen Kaye Et Al., *Do noninstitutional long-term care services reduce Medicaid spend*ing? 28 HEALTH AFF. 262 (2009).

[50] *Id*.

[51] Charlene Harrington, Terence Ng, & Martin Kitchener, *Do Medicaid Home and Community Based Service Waivers Save Money?* 30 HOME HEALTH CARE SERVICES Q. 198 (2011).

[52] H. Stephen Kaye., *Gradual Rebalancing of Medicaid Long-term Services and Supports Saves Money and Serves More People, Statistical Model Shows*, HEALTH AFFAIRS, June 2012.

[53] The Medicaid rehabilitation option is not discussed below due to the limited responses received from states concerning their experience with that option.

[54] Kaiser Commission on Medicaid and the Uninsured, Medicaid Home- and Community-Based Services Programs: Data Update (Washington, D.C.: December 2011).

[55] Alaska, Hawaii, Michigan, Minnesota, Missouri, New Mexico, New York, and Washington.

[56] Pub. L. 109-171, §6071, 120 Stat. 4

[57] These states include Colorado, Iowa, and Oregon.

[58] Wisconsin, New Mexico, California, and Connecticut.

[59] Alabama, Arkansas, Kentucky, Maryland, Minnesota, New York, Washington, and Wyoming.

[60] Alabama, Arkansas, Iowa, Minnesota, and Wyoming

[61] Pub. L. No. 111-148, §2401 (2010), 124 Stat. 119.

[62] Medicaid Program; Community First Choice Option, 76 Fed. Reg. 10,736 (February 25, 2011) (to be codified at 42 C.F.R pt. 441).

[63] Arizona, Maryland, Minnesota, and New York.

[64] Arkansas, Colorado, Connecticut, Michigan, and South Dakota.

[65] Alabama, Arkansas, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Maryland, Massachusetts, Michigan, Missouri, Nebraska, New York, Rhode Island, Tennessee, Texas, Virginia, and West Virginia.

[66] Florida, Georgia, Idaho, Indiana, Louisiana, Maine, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, South Carolina, and Utah.

[67] Indiana, Georgia, Louisiana, Mississippi, New Hampshire, and New Jersey.

[68] Pub. L. No. 109-171, §6071 (2006), 120 Stat. 4.

[69] Arkansas, California, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Maryland, Michigan, Missouri, Nebraska, New York, Oregon, Texas, Virginia, Washington, and Wisconsin..

[70] Colorado, Massachusetts, Minnesota, New Mexico, Rhode Island, Tennessee, Vermont, and West Virginia.

[71] Alabama and South Dakota.

[72] Pub. L. No. 97-35, §2176, 95 Stat. 357.

[73] *Id*.

[74] *Id*.

[75] *Id*.

[76] Alabama, Alaska, Arkansas, California, Colorado, Connecticut, Delaware, Hawaii, Illinois, Iowa, Kentucky, Maryland, Massachusetts, Michigan, Minnesota, Missouri, Nebraska, New Mexico, New York, Oregon, South Dakota, Tennessee, Texas, Virginia, Washington, West Virginia, Wisconsin, and Wyoming.

[77] P.L. 87-543, §122, 76 Stat. 172.

[78] See, KAISER FAMILY FOUNDATION, THE ROLE OF SECTION 1115 WAIVERS IN MEDICAID AND CHIP (2009).

[79] *Id*.

[80] *Id*.

[81] WENDY FOX-GRAGE, AARP PUBLIC POLICY INSTITUTE, AND JENNA WALLS, HEALTH MANAGEMENT ASSOCIATES, STATE STUDIES FIND HOME AND COMMUNITY-BASED SERVICES TO BO COST-EFFECTIVE, *available at* http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/state-studies-find-hcbs-cost-effective-spotlight-AARP-ppi-ltc.pdf.

[82] Arizona, Iowa, Maryland, Minnesota, Tennessee, and Washington.

[83] Connecticut, Colorado, New York, and Texas.

[84] Colorado, Maryland, Arizona, California, Iowa, Minnesota, New York, Tennessee, Texas, Washington.

[85] Arizona, Minnesota, Colorado, Texas, Washington, and New York.

[86] Tennessee, Connecticut, Iowa, Maryland.

[87] U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-649, MEDICAID STATES' PLANS TO PURSUE NEW AND REVISED OPTIONS FOR HOME- AND COMMUNITY-BASED SERVICES (2012).

[88] *Id*.

[89] California, Colorado, Connecticut, Iowa, Maryland, Minnesota, Tennessee, Texas, and Washington.

[90] California, Colorado, Connecticut, Maryland, Minnesota, New York, Texas, and Washington.

[91] Colorado, Maryland, New York, and Texas.

[92] California, Colorado, Connecticut, Iowa, Maryland, Minnesota, New York, Tennessee, Texas, and Washington.

[93] Colorado, Connecticut, Maryland, Minnesota, New York, Tennessee, Texas, Washington.

[94] Colorado, Connecticut, Iowa, and New York.

[95] Connecticut, Maryland, New York, and Washington.

[96] U.S. GOV'T ACCOUNTABILITY OFFICE, GAO-12-649, MEDICAID STATES' PLANS TO PURSUE NEW AND REVISED OPTIONS FOR HOME- AND COMMUNITY-BASED SERVICES (2012).

[97] CENTERS FOR MEDICARE & MEDICAID SERVICES, NURSING HOME DATA COMPENDIUM 2010 EDITION II (2010), *available at* http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/downloads/nursinghomedatacompendium_508.pdf. *See also*, Joseph Shapiro, *A New Nursing Home Population: The Young*, NPR (Dec. 9, 2010); Matt Sedensky, *Assisted Living: More Young People are Winding Up In Nursing Homes*, HUFFPOST (Jan. 7, 2011).

[98] Although the number of nursing home residents under 65 in nursing homes is growing, the percent of all adults age 30 and younger living in nursing homes is still less than one percent.

[99] DEP'T. OF HEALTH AND HUM. SERVS. OFFICE OF THE INSPECTOR GEN., OEI-08-0800360, HOME AND COMMUNITY-BASED SERVICES IN ASSISTED LIVING FACILITIES (2012).

[100] 77 Fed. Reg. 26361

[101] Alabama, Arizona, Arkansas, California, Connecticut, Delaware, Hawaii, Iowa, Kentucky, Massachusetts, Oregon, Virginia, Washington, and Wyoming. Many of these states' plans have been revised—or are in the process of being revised—since their initial release Texas, Vermont, and Wisconsin did not include specific information about their planning efforts as part of their responses; however, all three of these states have publically available *Olmstead* plans.

[102] Colorado, Illinois, Maryland, Michigan, Minnesota, Missouri, Nebraska, New Mexico, New York, Tennessee, and West Virginia.

[103] For a state-by state compilation of *Olmstead* related reports and websites see the University of California, San Francisco, National Center for Personal Assistance Services' report entitled Home and Community-Based Services: Introduction to Olmstead Lawsuits and Olmstead Plans. TERENCE NG ET. AL, UCSF NATIONAL CENTER FOR PERSONAL ASSISTANCE SERVICES, *HOME AND COMMUNITY-BASED SERVICES: INTRODUCTION TO* OLMSTEAD *LAWSUITS AND* OLMSTEAD *PLANS*,(updated April 2013), *available at* http://www.pascenter.org/Olmstead/.

[104] Alabama, Alaska, California, Colorado, Connecticut, Hawaii, Illinois, Iowa, Massachusetts, New Mexico, New York, Tennessee, Texas, Vermont, Washington, West Virginia, Wisconsin, and Wyoming.

[105] Arizona, Arkansas, Delaware, Kentucky, Minnesota, Missouri, and Oregon.