



**National Association of State Mental Health Program Directors**

**Behavioral Health and Community-Based Services in  
the Aftermath of Olmstead**

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## Executive Summary

Since the 1973 passage of § 504 of the Rehabilitation Act, Federal agencies administering Federally funded programs, such as Medicaid agencies and State Mental Health Agencies, have been mandated to eliminate segregation of individuals with disabilities. The 1990 Americans with Disabilities Act (ADA) and the implementing Federal regulations that followed accelerated the movement to eliminate segregation for individuals with disabilities. In passing the ADA, Congress said it had found that “discrimination against individuals with disabilities persists in such critical areas as ... institutionalization.”<sup>i</sup>

Title II of the ADA<sup>ii</sup> prohibited state and local government agencies, departments, special purpose districts, and other instrumentalities from discriminating against people with disabilities in their programs, services, and activities. Public entities were mandated to make reasonable modifications to their policies, practices, and procedures to allow equal opportunity for individuals with disabilities to participate, unless to do so would fundamentally alter the nature of the service, program, or activity. Title III of the ADA governing public accommodations and services made it discriminatory to, directly, or through contractual, licensing, or other arrangements: (A) deny opportunity to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations; (B) provide a benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to non-disabled individuals; or (C) provide a benefit different or separate from that provided to other individuals, unless necessary to provide a good, service, facility, privilege, advantage, or accommodation, or other opportunity that is as effective as that provided to others.<sup>iii</sup>

Most importantly, the Title II ADA regulations required a public entity to administer services, programs, and activities *in the most integrated setting appropriate* to the needs of qualified individuals with disabilities.<sup>iv</sup> The U.S. Attorney General subsequently defined the “most integrated setting appropriate” as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”<sup>v</sup>

The Supreme Court further accelerated the movement toward integrated settings with its decision in the 1999 *Olmstead v. L.C.* case.<sup>vi</sup> The Court found in *Olmstead* that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA. The *Olmstead* 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) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.<sup>vii</sup>

However, the *Olmstead* court noted that, “[s]ince 1981, Medicaid has provided funding for state-run home and community-based care through a waiver program” under §1915(c) of the Social Security Act.<sup>viii</sup> In fact, the Court noted, the Department of Health and

Human Services (HHS) often approves more slots under a waiver than the approved state ultimately uses.<sup>ix</sup>

The referenced §1915(c) waiver program provides a Federal Medicaid match to states for three years (an additional five years with the renewal of a waiver) for the provision of home- and community-based services (HCBS) to individuals who would otherwise require institutional care, but only if the average annual cost of such services is not more than the annual cost of institutional services. A §1915(c) waiver may include a waiver of the Medicaid requirement that a benefit be provided statewide<sup>x</sup> and/or that benefits be not less in duration, amount, or scope than benefits provided under the State Plan.<sup>xi</sup> In addition, §1915(c) authorizes providing under a waiver, for individuals with chronic mental illness, day treatment, partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility). Until 2005, the §1915(c) waiver was the mechanism states most frequently used to promote access to community-based services and supports for Medicaid. However, state HCBS waivers tended to primarily address developmental disability (including autism), elderly and individuals with disabilities, medically fragile and palliative care, and brain injury.

As of 2010, there were 284 § 1915(c) waivers in operation in 47 states and the District of Columbia. The three states not operating § 1915(c) waiver programs instead offered HCBS through their comprehensive § 1115 waiver programs.<sup>xii</sup> However, despite their pervasiveness, §1915(c) waivers over the years have far less frequently targeted individuals with mental illness and/or related conditions than other Medicaid populations. As of August 7, 2014, 16 states were operating 18 separate § 1915(c) waivers for individuals with mental illness, while 18 states offered 22 § 1915(c) waivers for individuals with brain injury. There were 55 separate 1915(c) waivers for individuals with autism in 32 states, either separately or as part of larger waivers designed for individuals with developmental disabilities.<sup>xiii</sup>

Under §6086 of the Deficit Reduction Act of 2005 (the DRA),<sup>xiv</sup> Congress enacted a State Plan option under § 1915(i) of the Social Security Act<sup>xv</sup> permitting states to serve individuals in the most integrated setting without need for a waiver or linkage to a need for an institutional level of care. States implementing § 1915(i) HCBS services would no longer be required to meet the “cost-neutrality” standard required for § 1915(c) HCBS waiver services. States would not need to produce cost estimate comparisons for institutional care and the State Plan benefit.<sup>xvi</sup> However, as enacted in the DRA, states were unable to target § 1915(i) services to particular populations within the State, and could only serve individuals whose incomes did not exceed 150 percent of the Federal poverty level (FPL). Additionally, the original service package available under § 1915(i) included some, but not all, of the HCBS available through waivers. To make the State Plan Option more attractive, Congress enacted § 2402(b) of the Affordable Care Act (ACA) to make additional changes to § 1915(i).

The ACA modifications to § 1915(i) specifically allow states to:

- provide services to individuals with income up to 300 percent of the Supplemental Security Income (SSI) Federal benefit rate (FBR) who would otherwise be eligible for HCBS under a § 1915(c), (d), or (e) waiver or § 1115 demonstration program;
- target the HCBS benefit to one or more state-specified population groups, through one or multiple five-year § 1915(i) service packages;
- make "other services" beyond State Plan services available to the population, including such services as behavioral supports, cognitive rehabilitative therapy, crisis intervention and counseling, health monitoring, family training, psychosocial rehabilitation services, partial hospitalization services, day treatment, and neuropsychology services; and
- allow any or all HCBS to be self-directed, in accordance with an individualized plan of care based on an independent assessment and a person-centered process driven by the beneficiary.<sup>xvii</sup>

As of August 2014, 18 states had submitted for approval State Plan Amendments (SPAs) to implement the 5-year § 1915(i) option and 12 SPAs had been approved by CMS. Arkansas, Delaware, and Maryland planned to implement the option in 2014. The District of Columbia, which was among the states whose SPA was approved earlier, planned to implement in 2014, Colorado in 2015.<sup>xviii</sup>

An additional option made available under § 2401 of the ACA was the "Community First Choice Option (CFC)" created under §1915(k) of the Social Security Act.<sup>xix</sup> The CFC option, which went into effect October 1, 2011, was created as a Medicaid State Plan optional benefit to provide home and community-based attendant services and supports. States that implement the CFC option are required to use a person-centered plan of services and supports, based on an assessment of functional need, and either be in an eligibility group that is entitled to receive nursing facility services or have an income not exceeding 150 percent of the federal poverty level (FPL).

CFC benefits may include HCBS attendant services—also called personal care and attendant care services—intended to enable people with disabilities and chronic conditions to remain in their homes and communities by providing them human assistance in performing basic activities of daily living (ADLs),<sup>xx</sup> instrumental activities of daily living (IADLs),<sup>xxi</sup> and health related tasks<sup>xxii</sup> they would do independently were it not for their disabilities.

States that implement the CFC option receive a six percentage point increase in their Federal Medical Assistance Percentage (FMAP) during operation of the program. As of May 2014, 10 states had submitted SPAs to CMS to implement the CFC option.<sup>xxiii</sup> However, a 2012 GAO report suggested that states seemed hesitant to apply for the CFC and the other options for home and community-based services included in the ACA due to budgetary concerns, lack of infrastructure, staff overburden and related hiring freezes, relative priority among all requirements and options authorized by the ACA, and a greater focus on broader Medicaid reform.<sup>xxiv</sup>

On March 17, 2014, after numerous false starts, CMS adopted final regulations governing the implementation of HCBS services.<sup>xxv</sup> The regulations, which apply to § 1915(c)

HCBS waivers and §1915(i) and (k) State Plan Option HCBS, prohibit the siting of HCBS—residential and non-residential—in nursing facilities, institutions for mental diseases, ICF/IID, and hospitals. In addition to these specific settings, the regulations state that “[a]ny setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution.” A process is created under which the Secretary determines through heightened scrutiny, based on information presented by the state or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home- and community-based settings.<sup>xxvi</sup> There’s a presumption that services provided in other institutional settings or adjacent or on the grounds of a public institution do not meet standards set for HCBS sites, but that presumption can be rebutted by the state as part of the state’s waiver or SPA submission to CMS.<sup>xxvii</sup> The presumption is overcome by demonstrating that the setting meets qualities listed in the regulations.

States submitting SPAs for new §1915(i) benefits must provide assurances of compliance with the new regulatory requirements as of the effective date of their proposed SPA. For any existing §1915(c) waivers or §1915(i) SPAs for which a state requests a renewal or amendment by March 17, 2015, the request must include a “transition plan,” to be approved by CMS, describing the deliverables to be addressed and the time table—no longer than five years—for bringing the state into compliance. If a state does not have an SPA or waiver to be re-approved or amended within, it must have until March 17, 2015 to submit its transition plan. Transition plans must be published by the state prior to submission to CMS to afford 30 days of public comment, and evidence of the public comment process must be included with the CMS submission.

While the final regulations apply to both residential and non-residential services, CMS acknowledged in January 2014 that there are issues specific to providing non-residential services traditionally provided in group settings which would need to be addressed in separate guidance. The agency held outreach discussions with interested stakeholders, including state Medicaid officials and Mental Health Agency directors to gain a better understanding of the specific issues that would have to be addressed. However, the guidance had still not been issued by August 2014 as agency officials continued to wrestle with how to provide services traditionally provided in group settings and involving group interaction while accommodating individual choice and preferences and any desire for the self-direction of services. The one basic principle enunciated by agency representatives was that non-residential services would have to meet all of the standards mandated for residential services, and that there would be no regulatory exceptions for non-residential services.

However, because states need to be able to describe how they will make the transition to community-based settings for non-residential services in the transition plans they must submit to CMS before March 16, 2015, and since some states have already been forced to supply bare bones transition plans with requests for extensions or amendments to existing

SPAs or waivers already submitted, making the guidance available becomes more critical for states with each passing day.

**This report makes the following recommendations:**

1. The § 1915(i) State Plan Option and the § 1915(k) Community First Choice Option provide more opportunities for developing and financing a greater variety of home- and community-based services in a more specifically targeted manner than ever before. Yet states so far have largely been reluctant to adopt those options. Inpatient services are becoming ever-less favored by federal agencies and most members of Congress every day, and continue to face opposition from behavioral health consumer advocates, but the demand for behavioral health services is growing, as is public interest in health care options generated by the publicity around the Affordable Care Act coverage. With demand growing and the financial ability to sustain state inpatient facilities diminishing, states should be exploring *now* how they can partner with CMS to broaden service options in home and community settings. In doing so, states should keep in mind that State Plan Amendments generally require years to develop and months for CMS approval, but that approval process time frame can be significantly reduced when a state reaches out early in development to seek CMS input into concepts and structure. States should be reaching out to CMS officials as soon as possible for ideas on how to creatively structure home- and community-based services to maximize federal financial participation.
2. CMS has required that state transition plans for HCBS—required to be included with submitted §1915(i) and (k) State Plan Amendments and requests for extensions or amendments to existing waivers, and by all states on or before March 16, 2015—be subject to a 30-day public comment, and that the public comment period be evidenced in transition plan submissions for approval. However, stakeholder input should begin long before transition plans are published for comment. States should be reaching out now to interested stakeholders to help them shape the elements of the required transition plans by identifying potential barriers—such as workforce or service shortages—to accessing their preferred home- and community-based services and providers.
3. As states strive to develop accurate and complete plans for the transition to home- and community-based settings, it becomes ever more critical that the states have a clear picture of what CMS expects with regard to standards for the siting of non-residential services. The promised guidance setting the standards for non-residential services, promised in January 2014, is still pending, with the deadline for final initial state transition plans only months away. Existing noncompliant providers will have to be retooled, or replaced by new community-based providers, and states will have to at least generally identify in their transition plans who those providers are to be and how they will be structured. It is imperative that CMS expedite the promised guidance on non-residential services to provide clarity for states, providers and their beneficiaries wishing to outline how they will access services.

## I. History of Discrimination by Placement in Non-Integrated Settings

Section 504 of the Rehabilitation Act of 1973<sup>xxviii</sup> was the first Congressional enactment to ban discrimination by recipients of federal funds against individuals on the basis of disability, and was modelled after previous laws enacted banning discrimination based on race, ethnic origin, and gender by those same federal fund recipients. It took a significant advocacy effort but, four years later, the Department of Health, Education and Welfare (HEW) issued the regulations implementing the law.<sup>xxix</sup>

For the first time, the exclusion and segregation of individuals with disabilities, including cognitive disabilities, was viewed as discrimination. The prevailing public assumption had previously been that the unemployment and low educational levels faced by individuals with disabilities were the consequences of the mental and physical limitations characteristic of the disabilities themselves. With enactment of § 504 of the Rehabilitation Act, Congress officially recognized that the inferior social and economic status of individuals with disabilities was instead a result of societal barriers and prejudices, and that federal legislation was needed to correct discriminatory policies and practices. People with disabilities were, for the first time, seen as a legitimate minority class, deserving of basic civil rights protections.

The evidence of the negative impact of providing care and services in segregated settings to individuals with mental illness was clear then, and remains clear even now, although it exists to a lesser degree. Unemployment levels among those with serious mental illness (SMI) in 2012 were 9.1 percent.<sup>xxx</sup> Compared with young adults without mental illness, young adults with any mental illness (AMI) and SMI were more likely to be unemployed (12.3 vs. 14.6 and 16.2 percent) and less likely to have full-time employment (38.3 vs. 33.0 and 29.7 percent). Adults between the ages of 18 and 25 with co-occurring SMI & substance use disorders are less likely to have a high school diploma and 1.4 times more likely to be unemployed or have unstable jobs.<sup>xxxi</sup>

In 1990, Congress enacted the Americans with Disabilities Act (ADA) “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.” In passing the groundbreaking ADA, Congress recognized that “historically, society has tended to isolate and segregate individuals with disabilities,” and, despite some improvements, these forms of discrimination against individuals with disabilities had continued well after passage of § 504. Congress noted that “discrimination against individuals with disabilities persists in such critical areas as . . . institutionalization.”<sup>xxxii</sup>

The ADA defined “disability” to mean disability' mean: (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an



impairment. Title II of the ADA prohibited discrimination in public services against “qualified individuals with a disability,” defining “discrimination” as excluding such an individual from participation in or being denied the benefits of, the services, activities, or programs of a “public entity.” A “public entity” was defined as a state or local government or department, agency, or other instrumentality of that government. A “qualified individual with a disability” was defined as an individual with a disability who, with or without reasonable modifications to rules, policies, or practices, the removal of architectural, communication, or transportation barriers, or the provision of auxiliary aids and services, meets the essential eligibility requirements for the receipt of services or participation in programs or activities provided by a public entity.

Title III addressed public accommodations and services operated by private entities. It defined public accommodation to include—among other things—a place of lodging, the professional office of a health care provider or hospital, and a day care center, senior citizen center, homeless shelter, or other social service center establishment. Title III made it discriminatory to, directly, or through contractual, licensing, or other arrangements: (A) deny opportunity to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of an entity; (B) provide a benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to non-disabled individuals; or (C) provide a benefit different or separate from that provided to other individuals, unless necessary to provide a good, service, facility, privilege, advantage, or accommodation, or other opportunity that is as effective as that provided to others.<sup>xxxiii</sup> Entities were required to provide goods, services, facilities, privileges, advantages, and accommodations to individuals with a disability in the most integrated setting appropriate to the needs of the individual.

Title III specifically listed the following acts as public accommodations discrimination:

- i. the imposition or application of eligibility criteria that screen out or tend to screen out an individual with a disability or any class of individuals with disabilities from fully and equally enjoying any goods, services, facilities, privileges, advantages, or accommodations, unless such criteria can be shown to be necessary for the provision of the goods, services, facilities, privileges, advantages, or accommodations being offered;
- ii. a failure to make reasonable modifications in policies, practices, or procedures, when such modifications are necessary to afford such goods, services, facilities, privileges, advantages, or accommodations to individuals with disabilities, unless the entity can demonstrate that making such modifications would fundamentally alter the nature of such goods, services, facilities, privileges, advantages, or accommodations;
- iii. a failure to take such steps as may be necessary to ensure that no individual with a disability is excluded, denied services, segregated or otherwise treated differently than other individuals because of the absence of auxiliary aids and services, unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered or would result in an undue burden;

- iv. a failure to remove architectural barriers, and communication barriers that are structural in nature, in existing facilities, and transportation barriers in existing vehicles and rail passenger cars used by an establishment for transporting individuals (not including barriers that can only be removed through the retrofitting of vehicles or rail passenger cars by the installation of a hydraulic or other lift), where such removal is readily achievable; and
- v. where an entity can demonstrate that the removal of a barrier under clause (iv) is not readily achievable, a failure to make such goods, services, facilities, privileges, advantages, or accommodations available through alternative methods if such methods are readily achievable.<sup>xxxiv</sup>

Title II of the ADA was to take effect 18 months after enactment, or by July 1992. Title III regulations were to be issued within one year of enactment. Comprehensive regulations and an interpretive appendix were issued in July 1991, one year before the effective date of the Act's employment discrimination provisions. The ADA regulations defined "mental impairment" to include "[a]ny mental or psychological disorder, such as . . . emotional or mental illness..."<sup>xxxv</sup> and adopted language similar to the ADA's statutory language prohibiting a public entity from:

- Denying a qualified individual with a disability the opportunity to participate in or benefit from the aid, benefit, or service;
- Affording a qualified individual with a disability an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others; or
- Denying a qualified individual with a disability the opportunity to participate in services, programs, or activities that are not separate or different, despite the existence of permissibly separate or different programs or activities.<sup>xxxvi</sup>

Most importantly to the discussion here, the Title II ADA regulations also required a public entity to administer services, programs, and activities ***in the most integrated setting appropriate*** to the needs of qualified individuals with disabilities.<sup>xxxvii</sup> The Attorney General defined the "most integrated setting appropriate" as "a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible."<sup>xxxviii</sup> The Supreme Court referred to that regulatory provision in its 1999 *Olmstead* decision<sup>xxxix</sup> as "the integration regulation."

The complexity of issues under the ADA moved the Equal Employment Opportunity Commission to issue a series of policy guidance documents designed to clarify and interpret the provisions of the law. Between 1993 and 1999, EEOC issued eight enforcement guidance documents which provided interpretations on key ADA issues, including one on employment discrimination based on psychiatric disability. That guidance defined psychiatric disability to mean "emotional or mental illness[es,]" including major depression, bipolar disorder, anxiety disorders (which include panic disorder, obsessive compulsive disorder, and post-traumatic stress disorder), schizophrenia, and personality disorders.<sup>xl</sup> The guidance said the current edition of the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental*

*Disorders* (DSM) could be used as guidance for identifying these disorders, but that not all conditions listed in the DSM were disabilities or even impairments under the ADA.

## II. The Olmstead Case

On June 22, 1999, the United States Supreme Court held, in *Olmstead v. L.C.*<sup>xli</sup> that unjustified segregation of persons with disabilities constitutes discrimination in violation of Title II of the ADA. The Olmstead 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) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.<sup>xlii</sup>

The *Olmstead* case was brought in 1995 by the Atlanta Legal Aid Society on behalf of Lois Curtis and Elaine Wilson, patients in a Georgia state psychiatric hospital with mental illness and developmental disabilities. The hospital staff had recommended that Lois and Elaine be served in community-based programs, but because community services were in short supply, they remained at the hospital. The State of Georgia asked the Supreme Court to decide: “[w]hether the public services portion of the federal Americans with Disabilities Act (ADA) compels the state to provide treatment and habilitation for mentally disabled persons in a community placement, when appropriate treatment and habilitation can also be provided to them in a state mental institution.”

In its 6 to 3 decision, the Supreme Court said that “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.” The Court said “... institutional confinement severely diminishes individuals’ everyday life activities...” and that “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. Dissimilar treatment correspondingly exists in this key respect: In order to receive needed medical services, persons with mental disabilities must, because of those disabilities, relinquish participation in community life they could enjoy given reasonable accommodations, while persons without mental disabilities can receive the medical services they need without similar sacrifice.”<sup>xliii</sup>

The Court acknowledged that “a State generally may rely on the reasonable assessments of its own professionals in determining whether an individual “meets the essential eligibility requirements” for habilitation in a community-based program. ... Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.” In this case, however, there was no dispute concerning the status of the two plaintiffs as individuals “qualified” for non-institutional care: The State’s own professionals had determined that community-based treatment would be appropriate, and neither woman had opposed such treatment.<sup>xliv</sup>

### III. § 1915(c) Home- and Community-Based Services (HCBS) Waivers

The *Olmstead* court noted that, “[s]ince 1981, Medicaid has provided funding for state-run home and community-based care through a waiver program” under §1915(c) of the Social Security Act.<sup>xlv</sup> In fact, the Court noted, the Department of Health and Human Services (HHS) often approves more slots under a waiver than a state ultimately uses. In fact, HHS had approved more than 2100 waiver slots for Georgia in the case, but the state had only filled 700.<sup>xlvi</sup>

The §1915(c) waiver program provides Medicaid reimbursement to states for three years (an additional five years with the renewal of a waiver) for the provision of community-based services to individuals who would otherwise require institutional care, if the average annual cost of such services is not more than the annual cost of institutional services. A §1915(c) waiver may include a waiver of the Medicaid requirement that a benefit be provided statewide<sup>xlvii</sup> and/or that benefits be not less in duration, amount, or scope than benefits provided under the State Plan.<sup>xlviii</sup> Section 1915(c)(4) specifically mentions, as permissible services under HCBS waivers: case management, homemaker/home health aide services, personal care services, adult day health services, habilitation services, respite care, and other services approved by the Secretary of HHS. In addition, §1915(c) authorizes providing under a waiver, for individuals with chronic mental illness, day treatment, partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility).

Until 2005, the §1915(c) waiver was the mechanism that states most frequently used to promote access to community-based services and supports for Medicaid. However, historically, state HCBS waivers have targeted individuals with developmental disabilities (including autism), elderly and individuals with disabilities, individuals who are medically fragile or need palliative care, and individuals with brain injury. They have far less frequently covered mental illness.

Of course, the official classification of waivers by type is not always precise. Some waivers are broad or inclusive in the way they are written and are not easily classifiable, and some waiver titles are unclear or misleading. In fact, some waiver titles were unrelated or related only partially to the population served. Nevertheless, as of 2010, there were 284 § 1915(c) waivers in operation in 47 states and the District of Columbia. No state operating HCBS waivers had fewer than 4.<sup>xlix</sup> The three states not running § 1915(c) waiver programs—Arizona, Rhode Island, and Vermont—instead offered home and community-based services through comprehensive § 1115 waiver programs.<sup>1</sup>

In 2010, the latest date for which data is available, 1.4 million beneficiaries accessed Medicaid services through a § 1915(c) HCBS waiver, an 80 percent increase of the number of participants in the year 2000. Expenditures on § 1915(c) HCBS services in 2010 were at \$36.8 billion, almost three times the \$12.6 billion in expenditures in 2000 for § 1915(c) HCBS services.

However, despite their pervasiveness, §1915(c) waivers over the years have far less frequently targeted individuals with mental illness and/or related conditions than other Medicaid populations.<sup>li</sup> As of August 7, 2014, only 16 states were operating 18 separate § 1915(c) waivers for individuals with mental illness, while 18 states offered 22 § 1915(c) waivers for individuals with brain injury. There were 55 separate 1915(c) waivers for individuals with autism in 32 states, either separately or part of larger waivers designed for individuals with developmental disabilities.<sup>lii</sup>

The robustness of the service packages vary by state, with descriptions of services in the Montana and Wisconsin approved waiver applications indicating those states aspire to offer the most robust packages of services.

Montana's Adults with Severe Disabling Mental Illness Waiver affords enrollees adult day health, case management, day habilitation, homemaker services, prevocational services, residential habilitation, respite care, supported employment, occupational therapy, adult residential care, chemical dependency counseling, handling of chores, dietitian/nutrition/meals, habilitation aides, illness management and recovery, non-medical transportation, personal assistance service/specially trained attendant care, a personal emergency response system (PERS), private duty nursing (and registered nurse supervision), psychosocial rehabilitation, specialized medical equipment and supplies, and supported living.<sup>liii</sup>

Wisconsin's waiver offers many of the same services and more, including consumer education and training, day services, respite care, support and service coordination, supported employment, supportive home care, consumer- and family-directed supports, functional movement screens (FMS), adaptive aids, adult family home care, children's foster care/treatment foster care, communication aids, community integration, consultative behavioral intervention, counseling and therapeutic services, daily living skills training, early intensive behavioral intervention, home modifications, housing counseling, housing start up, mentoring, nursing, PERS, specialized transportation, and specialized medical and therapeutic supplies.<sup>liv</sup>

#### **IV. §1915(i) State Plan Option HCBS**

With passage of §6086 of the Deficit Reduction Act of 2005,<sup>lv</sup> Congress enacted a State Plan option under § 1915(i) of the Social Security Act<sup>lvi</sup> permitting states to serve individuals in the most integrated setting without need for a waiver or linkage to the individual's need for an institutional level of care. As originally enacted, however, states were unable to target § 1915(i) services to particular populations, and could only serve individuals whose incomes did not exceed 150 percent of the Federal poverty level (FPL). Additionally, the original service package available under § 1915(i) included some, but not all, of the HCBS available through waivers.

Section 2402(b) of the Affordable Care Act made additional changes to § 1915(i) designed to make the State Plan option even more attractive. Under the ACA

amendments, programs can continue to specify needs-based eligibility criteria, but services must be provided statewide, and, unlike waiver programs, cannot have enrollment caps or waiting lists. However, states have the ability to reduce their § 1915(i) needs-based eligibility criteria without CMS approval when they exceed their projected number of beneficiaries served, as long as they provide 60 days' prior notice and grandfather coverage for existing beneficiaries.

Section 1915(i) specifically allows states to:

- continue to have the option to provide State Plan HCBS to individuals with incomes up to 150 percent of the FPL who are eligible for Medicaid under an eligibility group covered under the State plan, with non-financial needs-based criteria less stringent than the need for an institutional level of care;
- provide services to individuals with income up to 300 percent of the Supplemental Security Income (SSI) Federal benefit rate (FBR) who would otherwise be eligible for HCBS under a § 1915(c), (d), or (e) waiver or § 1115 demonstration program;
- target the HCBS benefit to one or more state-specified population groups, through one or multiple five-year § 1915(i) service packages;
- make "other services" beyond State Plan services available to the population, including such services as behavioral supports, cognitive rehabilitative therapy, crisis intervention and counseling, health monitoring, family training, psycho-social rehabilitation services, partial hospitalization services, day treatment, and neuropsychology services; and
- allow any or all HCBS to be self-directed, if there exists an individualized plan of care based on an independent assessment and a person-centered process driven by the beneficiary.<sup>lvii</sup>

States implementing § 1915(i) HCBS services need not meet the "cost-neutrality" standard required for § 1915(c) HCBS waiver services, so they need not produce cost estimates comparing the costs of institutional care and the State Plan benefit. CMS says this significant distinction is what allows the states to offer HCBS to individuals whose needs are not severe enough to qualify for institutional services.<sup>lviii</sup>

States can also provide Medicaid services in a home- and community-based setting to individuals who would otherwise be eligible only in an institutional setting due to the income and resources of their spouse or parent. States use spousal impoverishment rules to determine financial eligibility for waiver services.

As of August 2014, 18 states had submitted for approval SPAs to implement the 5-year § 1915(i) option and 12 SPAs had been approved by CMS. This was two more than the 10 states (California, Connecticut, District of Columbia, Florida, Iowa, Idaho, Louisiana, Nevada, Oregon and Wisconsin) approved by 2012<sup>lix, lx</sup>; Indiana, Montana and Colorado had been added to the approved list by August 2014, Texas and Washington State had withdrawn approved SPAs, while Arkansas, Delaware, and Maryland planned to implement the option in 2014. The District of Columbia, which was among the states whose SPA was approved earlier, planned to implement in 2014, Colorado in 2015.<sup>lxi</sup>

## Examples of Recently Approved § 1915(i) State Plan Amendments

States have found the option has particular promise for improving access to community-based services for individuals with mental and substance use disorders, a group which, as noted previously, has generally been under-represented in waiver populations. For instance, Montana's §1915(i) program, for Youth with Serious Emotional Disturbances, approved by CMS in September 2013, is designed for Medicaid-eligible youth, ages 5 through 17, or to the age of 20 if the youth is still in secondary school and consents to participation. A participating youth must have had at least one admission to a Psychiatric Residential Treatment Facility (PRTF), a local in-patient hospital related to behavioral health needs, or a therapeutic group home in the previous 12 months, or be at risk of placement in a PRTF, and also be receiving three or more of the following types of outpatient services: outpatient therapy with or without medication management; comprehensive school and community treatment; day treatment or partial hospitalization; therapeutic family care or therapeutic foster care; or respite.

The Montana program offers:

- peer-to-peer services provided by community agencies to support the youth in making informed independent choices, coach the youth in developing systems advocacy skills, and assist the youth and his/her family in developing formal and informal community supports;
- consultative clinical and therapeutic services by treating physicians and mid-level practitioners with access to psychiatric expertise and consultation in the areas of diagnosis, treatment, behavior, and medication management;
- supplemental supportive services and goods not reimbursed by Medicaid (limited to \$1,000 annually);
- education and support services for family members and unpaid caregivers that include instruction about the diagnostic characteristics and treatment regimens for the youth, including medication and behavioral management;
- family support specialist for the youth's family unit, to provide: family therapy; education about the youth's illness; coaching, supporting and encouraging parenting techniques; providing parenting skills specific to the child; participating in family activities to change family dynamics; working with youth to access wellness recovery tools; and serving as a member of a crisis intervention team;
- face-to-face, individual, and family in-home therapy for the youth and his/her parents that includes developing and writing an individual treatment plan, providing 24/7 crisis response, assisting with transition planning, and attending family and team meetings;
- transportation by agencies through common carrier or private vehicles to and from social or other nonmedical activities included in the service plan;
- short-term respite care for the youth when the unpaid persons normally providing day to day care for the youth are not available to provide care;
- high-fidelity wraparound facilitation, comprised of a variety of specific tasks and activities designed to support the family and youth in identifying, prioritizing, and achieving their goals within a team of the family's choosing, under the supervision of a licensed mental health professional;

- specialized evaluation services with brief consultation otherwise unavailable or not covered by State Plan Medicaid or other funding sources;
- crisis intervention services, which include a short-term (not greater than 14 days) placement in a therapeutic group home or youth shelter home when intervention and short-term placement are necessary to avoid escalation and acute care admission; and
- co-occurring services, provided by a licensed addiction counselor in conjunction with a licensed mental health professional, that are designed to provide assessment/evaluation, education and treatment for co-occurring mental health and chemical dependency issues through an integrated approach.<sup>lxii</sup>

The Indiana Home and Community Based Service- Behavioral and Physical Health Coordination § 1915(i) SPA, implemented retroactively April 1, 2014, after approval by CMS on May 30, 2014, works concurrently with the state’s earlier-approved § 1915(b)(4) waiver to allow for selective contracting of providers of behavioral and physical health coordination, specifically community mental health centers (CMHCs). The § 1915(b)(4) waiver provides for Adult Mental Health Habilitation and Behavioral and Primary Healthcare Coordination Services. The § 1915(i) coordination service is to be provided for beneficiaries age 19 and older with a primary mental health diagnosis who are living in a residential setting. If the § 1915(b)(4) waiver expires, the § 1915(i) SPA is no longer valid.<sup>lxiii</sup>

A beneficiary receiving the approved coordination service under the Indiana SPA must have demonstrated needs related to the management of his or her behavioral and physical health and impairment in self-management of the same, with a health need that requires assistance and coordination support. An assessment conducted by an independent, conflict-free assessment team must have recommended intensive community-based care on the state’s uniform assessment tool. The SPA defines “impairment in self-management of physical and behavioral health” as “a limited or impaired ability to carry out routine healthcare regimens, including taking medicine as prescribed, keeping medical appointments, maintaining linkage with a primary care provider, diet, exercise, and management of symptoms.”

Beneficiaries are provided a list of providers in the geographic area from whom they may choose. Interventions are developed in collaboration with the individual, the treatment team, and when appropriate the beneficiary’s family or guardian.<sup>lxiv</sup>

## **V. §1915(k) Community First Choice State Plan Option**

Section 2401 of the ACA established what it called the “Community First Choice Option (CFC)” under §1915(k) of the Social Security Act.<sup>lxv</sup> The CFC option, which went into effect October 1, 2011, was created as a Medicaid State Plan optional benefit to provide home and community-based attendant services and supports. Individuals served under the CFC option must either be in an eligibility group that is entitled to receive nursing facility services or have an income not exceeding 150 percent of the federal poverty level (FPL). States that implement the option are required to use a person-centered plan of services



and supports, based on an assessment of functional need, which must be agreed to in writing by the individual or the individual's representative.

CFC benefits may include attendant services—also called personal care and attendant care services—home and community-based services (HCBS) intended to enable people with disabilities and chronic conditions to remain in their homes and communities by providing them human assistance in performing basic activities of daily living (ADLs),<sup>lxvi</sup> instrumental activities of daily living (IADLs),<sup>lxvii</sup> and health related tasks<sup>lxviii</sup> they would do independently were it not for their disabilities.

States electing the CFC option must make available to eligible Medicaid beneficiaries hands-on assistance (actually performing a task for a person) or supervision and cueing so beneficiaries can accomplish everyday tasks for themselves. In addition to attendant services, CFC funds may be used to support:

- back-up systems or mechanisms to ensure continuity of services and supports (such as the use of beepers or other electronic devices); and
- voluntary training on selecting, managing, and dismissing attendants.

States also have the flexibility to cover, under the CFC option, transition costs associated with moving from an institution to a home- or a community-based setting, such as security deposits for an apartment or utilities, basic kitchen supplies, or bedding and other necessities required for transition, as well as expenditures, related to a need identified in the individual's person-centered service plan, that increase independence or purchase a substitute for human assistance. The CFC statute excludes from coverage any costs related to room and board, as well as special education otherwise provided under the Individuals with Disabilities Education Act (IDEA). Costs related to assistive technologies, medical supplies and equipment, or home modifications are also excluded, except to the extent they are specified in the beneficiary's person-centered care plan as necessary to increase independence or substitute for human assistance.

States that implement the CFC option receive a six percentage point increase in their Federal Medical Assistance Percentage (FMAP) during operation of the program.

As of May 2014, 10 states had submitted SPAs to CMS to implement the CFC option for home and community-based attendant services and supports, although two states (Arizona and Louisiana subsequently withdrew their State Plan Amendments). Of the remaining eight states, CMS had approved three SPAs (California, Maryland, and Oregon), and an additional five states (Arkansas, Minnesota, Montana, Texas, and Wisconsin) planned to implement the option in 2014.<sup>lxix</sup> A 2012 GAO report suggested that states seemed to be hesitant to apply for the CFC option and the other options for home and community-based services included in the ACA due to budgetary concerns, lack of infrastructure, staff overburden and related hiring freezes, relative priority among all requirements and options authorized by the ACA, and a greater focus on broader Medicaid reform.<sup>lxx</sup> In its 2014 Interim Report to Congress, CMS also reported that states seemed to be weighing the loss of the ability provided under § 1915(c) waivers to limit

the number of program participants, against the value of the enhanced federal matching rate for the State Plan option.<sup>lxxi</sup>

### Examples of Recently Approved § 1915(k) CFC Option Programs

Among the states launching CFC option programs, the benefits offered are varied. The Maryland Community First Choice Option program includes among its benefits personal assistance services, Personal Emergency Response Systems (PERS), assistive technology, environmental assessments, accessibility adaptations, consumer training, supports planning, transition services, nurse monitoring, and home-delivered meals.<sup>lxxii</sup>

In contrast, the California Community First Choice Option program provides:

- assistance with household chores, such as dusting, sweeping and mopping;
- heavy cleaning of the home to remove hazardous debris or dirt;
- meal preparation, laundry, and shopping;
- personal care services, such as eating, grooming, and bathing;
- paramedical services performed by an attendant related to the needs of the beneficiary, directed by licensed health care professionals;
- protective supervision, i.e. observing behavior and intervening as appropriate in order to safeguard the recipient against injury, hazard, or accident; and
- yard hazard abatement, including removal of high weeds, rubbish, ice and snow, and other hazardous substances which constitute a hazard.<sup>lxxiii</sup>

California also provides for the acquisition, maintenance, and enhancement of skills through teaching and demonstration by social workers chosen by the beneficiary, as necessary to achieve greater independence. This support is initially limited to three months, but if the individual does not acquire the skills after three months, the services are re-authorized as needed in the individual's person-centered plan.

The services provided under Oregon's Community First Choice Option "K Plan," in addition to ADL and IADL attendant care services, include:

- community transportation;
- electronic back-up systems or assistive devices (durable medical equipment not covered by other available resources, electronic devices – to increase or maintain an individual's independence) (limited to \$5,000);
- once daily home-delivered meals (if individuals are home-bound, unable to do meal prep and have no other person available to prepare meals);
- contracted nursing services;
- training for individuals and representatives regarding employer responsibilities;
- environmental modifications (limited to \$5,000); and
- transition costs for housing for individuals relocating from an institutional setting (Intermediate Care Facility for Individuals with Intellectual and Developmental Disabilities (ICF/IDD), Institution for Mental Illness for those 21 and younger or

65 and older, hospitals, or nursing facility).<sup>lxxiv</sup>

## **VI. History of Federal HCBS Regulations and the Determination of Appropriate Settings**

Left undetermined after years of states developing, and CMS approving, HCBS waivers and HCBS state plan options, was what exactly constituted a home- and community-based setting.

As noted above, the § 1915(i) State Plan option HCBS provision was enacted as § 6086 of the Deficit Reduction Act of 2005, enacted in February 2006. CMS proposed to amend the Medicaid regulations in April 2008<sup>lxxv</sup> to implement § 6086, but that proposed rule was never finalized and, with passage of § 2402 of the ACA, some of the proposed regulations no longer reflected the amended provisions of §1915(i).

CMS proposed regulations to implement the CFC option in February 2011.<sup>lxxvi</sup> Those regulations proposed to bar home- and community-based services in a nursing facility, an institution for mental diseases, an intermediate care facility for the mentally retarded, or any setting located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment or custodial care. Also barred were services provided in a building of or on the grounds of or immediately adjacent to, a public institution or disability-specific housing complex geographically segregated from the larger community.

The reaction from many of the states to the barring of HCBS services on the grounds of or adjacent to institutional facilities was immediate and strong, particularly in those states where institutional settings still far outnumber community settings. Tennessee Medicaid Director Darin Gordon told CMS in TennCare's written comments on the proposed regulatory language:

The criteria CMS proposes to use to determine whether a setting is home- and community-based are neither practical to apply nor objective. The exclusion of several types of facilities in which HCBS waiver participants have chosen to receive services interferes with their freedom of choice, and will result in unnecessary institutionalization of waiver participants that could otherwise be safely and cost-effectively served in more integrated settings of their choice. States will likely not have a ready supply of alternatives which CMS deems "home and community based" under its new interpretations, and residents who have chosen to live in these settings will be forced into institutions—not because of the States' actions, but because of CMS regulations. Moreover, this will greatly impede States' efforts to develop new community-based residential alternatives, as providers who can survive the economic impact of these changes will be wary of assuming additional risk in developing new alternatives that may also be deemed (over time) to be not home and community-based "enough."<sup>lxxvii</sup>

Officials of 23 other state Medicaid agencies<sup>lxxviii</sup> joined with Tennessee in a second letter

expressing similar reservations about separately proposed regulations intended to govern settings for 1915(c) Home and Community-Based Services.<sup>lxxix</sup> That proposed rule included “three categorical prohibitions against siting HCBS (1) in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment or custodial care; (2) in a building on the grounds of, or immediately adjacent to, a public institution; or (3) in a housing complex designed expressly around an individual’s diagnosis or disability.

The commenting states said they supported the goal of promoting integrated community living settings, but that the proposal was “likely to limit recipients’ choices without meaningfully advancing the goal of community integration.”<sup>lxxx</sup> The states said they believed “that the proposed rule will make waiver services unavailable to individuals who do not need to reside in a nursing home or ICF/MR but who do need and desire supports available only in settings that the proposed rule deems insufficiently integrated.”

The responding states also warned:

Many of the individuals who will be forced to move if CMS adopts the proposed rule have already relocated at least once. Across the country, many large institutions have been closed in favor of small housing units built on the grounds of the former institutions. Individuals who moved from such an institution to a non-institutional setting that CMS would now deem insufficiently integrated in the community do not deserve to be uprooted yet again. Closure of such housing and relocation of the residents is an unconscionable burden on the states and on the affected beneficiaries.

Furthermore, the proposed rule may prevent individuals currently residing in congregate and/or assisted living settings from receiving services that would promote further independence and integration. The Commenting States strongly believe that, in most cases, the provision of HCBS fosters recipients’ ability to function at a higher level, thus creating opportunities for them to move into more independent and individualized living arrangements. By denying § 1915(c) waiver services to individuals who have taken an intermediate step toward fuller independence, the proposed rule will prevent them from making further progress.

In May 2012, CMS again proposed regulations to define and describe State Plan HCBS services, this time adding the changes under the ACA. The proposed rule incorporated changes made by CMS in response to the comments submitted on the 2011 proposed regulations, aligning the language on appropriate settings for § 1915(k) CFC option programs with appropriate settings for § 1915(i) State Plan Option programs and § 1915(c) waiver HCBS programs. Before publication of the 2012 proposed regulations, CMS had solicited stakeholder comment on appropriate settings for HCBS services and had facilitated numerous stakeholder conversations.

The 2012 proposed regulations proposed to require that home- and community-based settings exhibit the following qualities, based on the needs of the individual as indicated in their person-centered service plan, in order to be eligible sites for delivery of HCBS:

- The setting is integrated in, and facilitates the individual’s full access to, the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, like individuals without disabilities;
- The setting is selected by the individual among all available alternatives and identified in the person-centered service plan;
- An individual’s essential personal rights of privacy, dignity and respect, and freedom from coercion and restraint are protected;
- The setting optimizes individual initiative, autonomy, and independence in making major life choices, including but not limited to, daily activities, physical environment, and with whom to interact are optimized and not regimented; and
- Individual choice regarding services and supports, and who provides them, is facilitated.<sup>lxxxii</sup>

CMS again stated, as it had in the 2011 proposed regulations, that home and community-based settings could not include nursing facilities, institutions for mental diseases, or intermediate care facilities for mentally retarded, and also specifically added hospitals to the list of prohibited settings, as well as “any other locations that have the qualities of an institutional setting as determined by the Secretary.”<sup>lxxxiii</sup>

For the first time, CMS said that, in considering whether a setting has the qualities of an institutional setting, the agency would exercise a rebuttable presumption that a setting is not a home and community-based setting, and would “engage in heightened scrutiny” for any setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or disability-specific housing complex.<sup>lxxxiii</sup>

CMS promised to issue additional guidelines, but also warned that characteristics that could cause CMS to consider a setting as “institutional” or having the qualities of an institution would include, but not be limited to, settings which:

- are isolated from the larger community,
- do not allow individuals to choose whether or with whom they share a room,
- limit individuals’ freedom of choice on daily living experiences such as meals, visitors, and activities, or
- limit individuals’ opportunities to pursue community activities.<sup>lxxxiv</sup>

In a provider-owned or -controlled residential setting, CMS said the following additional conditions would have to be met. Any modification of the conditions—for example to address the safety needs of an individual with dementia—would have to be supported by specific assessed needs and documented in the individual’s person-centered service plan:

- The unit or room is a specific physical place that can be owned, rented or occupied under another legally enforceable agreement by the individual receiving services, and the individual has, at a minimum, the same responsibilities and protections from eviction that the tenants have under the landlord tenant laws of the State, county, city, or other designated entity.

- Each individual has privacy in their sleeping or living unit.
- Units have lockable entrance doors, with only appropriate staff having keys to doors.
- Individuals share units only at their own choice.
- Individuals have the freedom to furnish and decorate their sleeping or living units.
- Individuals have the freedom and support to control their own schedules and activities, and have access to food at any time.
- Individuals are able to have visitors of their choosing at any time.
- The setting is physically accessible to the individual.<sup>lxxxv</sup>

## VII. Current Federal HCBS Regulations

On March 17, 2014, CMS adopted final regulations governing the implementation of HCBS services.<sup>lxxxvi</sup> The regulations, which apply to § 1915(c) HCBS waivers and §1915(i) and (k) State Plan Option HCBS, formally and finally prohibit the siting of HCBS—residential and non-residential—in the institutional settings specified in the previous iterations of the regulations, i.e. nursing facilities, institutions for mental diseases, ICF/IID, and hospitals; CMS notes that these settings are prohibited under the various underlying statutory authorities.

In addition, the final regulations state that, in addition to the specific settings,

“[a]ny setting that is located in a building that is also a publicly or privately operated facility that provides inpatient institutional treatment, or in a building on the grounds of, or immediately adjacent to, a public institution, or any other setting that has the effect of isolating individuals receiving Medicaid HCBS from the broader community of individuals not receiving Medicaid HCBS will be presumed to be a setting that has the qualities of an institution unless the Secretary determines through heightened scrutiny, based on information presented by the state or other parties, that the setting does not have the qualities of an institution and that the setting does have the qualities of home- and community-based settings.”<sup>lxxxvii</sup>

Under this process, there’s a presumption that services provided in other institutional settings or adjacent or on the grounds of a public institution do not meet standards set for HCBS sites, but that presumption can be rebutted by the state as part of the state’s waiver or SPA submission to CMS.<sup>lxxxviii</sup> The presumption is overcome by demonstrating that the setting meets [qualities](#) listed in the regulations.

In the preamble to the final regulations, in an apparent response to some of the concerns expressed by the states in 2011, CMS notes that while HCBS cannot be available while an individual resides in an institution, HCBS may be available to assist individuals to transition from an institution to the community. With an acknowledgment that individuals leaving institutions require assistance to establish themselves in the community, CMS

says it will allow states to include in a § 1915(i) benefit, as an “other” service, transition services begun prior to an individual’s discharge that are being used to assist individuals during the period of transition from an institutional residence. Additionally, services can be provided to assist individuals transitioning to independent living in the community.<sup>lxxxix</sup>

In addition, CMS says it recognizes that, for short hospital stays, an individual may benefit from ongoing support through the State Plan HCBS benefit to meet needs not met through the provision of hospital services that are identified in the individual’s person-centered service plan, to ensure smooth transitions between acute care settings and home and community-based settings, and to preserve the individual’s functions. Where these services are provided, CMS said, they must be exclusively for the benefit of the individual, not the hospital, and must not substitute for services that the hospital is obligated to provide through its conditions of participation or under federal or state laws.<sup>xc</sup>

The final regulations adopt, with only minor non-substantive changes to the wording of the 2012 proposed regulations, the list of [qualities](#) that CMS says HCBS settings must exhibit.<sup>xc<sup>i</sup></sup> Similarly, the regulations adopt the requirements proposed in 2012 for [provider-owned or -controlled residential settings](#), with the additional stipulation that, for settings in which landlord tenant laws do not apply, the state must ensure there is a lease, residency agreement, or other form of written agreement in place for each HCBS participant, and that the document provides protections that address eviction processes and appeals comparable to those provided under the jurisdiction’s landlord tenant law.<sup>xc<sup>ii</sup></sup>

The final regulations specify that the options from which the beneficiary chooses a setting must be documented in the beneficiary’s person-centered plan and must be based on the beneficiary’s needs and preferences and, for residential settings, his or her available resources for room and board.<sup>xc<sup>iii</sup></sup> When a modification of the requirements is necessary and documented in the person-centered plan, CMS now specifies that the documentation in the plan must identify a specific and individualized assessed need and document the positive interventions and supports used prior to the modifications, as well as less intrusive methods of meeting the need that have been tried but did not work, and include a clear description of the condition modified that is directly proportionate to the specific assessed need. The person-centered plan must also include a regular collection and review of data to measure the ongoing effectiveness of the modification, have established time frames for periodic reviews to determine if the modification is still necessary or can be terminated, and include the informed consent of the individual with an assurance that the modified intervention(s) and/or support(s) will cause no harm to the individual.<sup>xc<sup>iv</sup></sup>

States submitting SPAs for new §1915(i) benefits must provide assurances of compliance with the regulatory requirements as of the effective date of the SPA. For any existing §1915(c) waivers or §1915(i) SPAs for which a state requests a renewal or amendment by March 17, 2015, the request must include a “transition plan,” to be approved by CMS, describing the time table—no longer than five years—for bringing the state into compliance and the deliverables to be addressed. If a state does not have an SPA or waiver to be re-approved or amended within that time, it has until March 17, 2015 to

submit its transition plan. Transition plans must be published to afford 30 days of public comment prior to submission to CMS, and evidence of the public comment process must be included with the CMS submission.

In public dialogue regarding the final HCBS regulations with state stakeholders, CMS stressed repeatedly that services not qualifying for coverage as HCBS services under the regulations could still qualify for reimbursement if they met the statutory and regulatory requirements for §1905(a) services. A failure to meet the HCBS standards does not mean the services can't be covered, but only that they can't be covered as HCBS services.

### **Guidance on Non-Residential Services**

While the final regulations apply to both residential and non-residential services, CMS acknowledged in January 2014 that there are issues specific to providing non-residential services traditionally provided in group settings which would need to be addressed in separate agency guidance. The agency held outreach discussions with interested stakeholders, including state Medicaid and Mental Health Agency officials, to gain a better understanding of specific issues that would have to be addressed for non-residential services sited in community-based settings. However, the guidance had still not been issued by August 2014 as agency officials continued to wrestle with how to provide services traditionally provided in group settings and involving group interaction while accommodating individual choice and preferences and any desire for the self-direction of services. The one basic principle enunciated by agency representatives was that non-residential services would have to meet all of the standards mandated for residential services, and that there would be no regulatory exceptions for non-residential services.

However, since states must be able to describe how they will make the transition to community-based settings for non-residential services in the transition plans they must submit to CMS before March 16, 2015, and since some states have already been forced to supply only bare bones transition plans with requests for extensions or amendments to existing SPAs or waivers already submitted, making the guidance available becomes more critical with each passing day.

### **VIII. Targeting Benefits for HCBS Services**

With passage of the ACA, states are permitted to target HCBS benefits to specific populations, through one or multiple §1915(i) service packages, without the need to ensure that the benefits are comparable in amount, duration, and scope to benefits provided to beneficiaries outside the § 1915(i) package. The state must describe the population groups receiving State Plan HCBS in the SPA, and State Plan HCBS populations must fall within some combination of the following population categories: age, diagnosis, disability, and Medicaid-eligibility. As noted previously, a state may elect in its SPA to limit availability of specific services to vary the amount, duration, or scope of services to one or more of the groups.<sup>xcv</sup> Targeting criteria cannot have the impact of limiting the pool of qualified providers from which an individual can receive



services, or have the impact of requiring the individual to receive services from the same entity from which they purchase housing.

State Plan HCBS services must include on or more of the following: case management services, homemaker services, home health aide services, personal care services, adult day health services, habilitation services, and respite care services. The final regulations continue to require that services for individuals with chronic mental illness continue one or more of: day treatment or other partial hospitalization services, clinic services, whether or not furnished in a facility, and/or psychosocial rehabilitation services. The state may also include additional state-specified services approved by HHS.<sup>xcvi</sup>

The state must establish needs-based criteria, which may include risk factors, for determining an individual's eligibility under the State Plan for the HCBS benefit in general, and may establish needs-based criteria for each specific service.<sup>xcvii</sup> The state must annually provide CMS an estimate of the number of individuals expected to be enrolled in each HCBS benefit and the number of individuals enrolled in State Plan HCBS the previous years. The state may not limit access to services for the elderly and individuals with disabilities based on the income of the otherwise eligible individuals, the cost of services, or the individual's location in the state.<sup>xcviii</sup>

A state may limit enrollment or the provision of services to enrolled individuals based on criteria described in a phase-in plan, subject to CMS approval, that describes the criteria being used to limit enrollment and service delivery, the rationale for the phase-in, timelines and benchmarks for ensuring the benefit is available to all eligible individuals within the initial 5-year approval period. If phase-in is to be based on highest need, the needs-based criteria for enrollment must be based on assessed needs of individual beneficiaries, with those with higher needs receiving services before those with lesser needs. If the state is phasing in services, the phase-in plan must include a description of the services that will not be available to all eligible individuals, the rationale for limiting services, and an assurance that all individuals with access to a willing and qualified provider will receive services. The plan must include a timeline for the phase-in of all services before the end of the initial 5-year approval period.<sup>xcix</sup>

## **IX. The Person-Centered Service Plan**

A diagnosis is not considered a sufficient factor on which to base a determination of a beneficiary's need; a criterion for services will only be considered needs-based if it is determined through an individualized evaluation of the beneficiary's need for support, performed face-to-face or through telemedicine, by a qualified, independent, conflict-free agent, in consultation with the individual consumer beneficiary, the beneficiary's family, and/or other designated person, using only current information from existing records. Each individual receiving the 1915(i) benefit must be re-evaluated every 12 months to determine whether he or she continues to meet the eligibility requirements.<sup>c</sup>

The process for developing the person-centered plan must include individuals chosen by the beneficiary, provide necessary information and support to ensure the individual

directs the process to the maximum extent possible and can make informed choices, is timely and occurs at times and locations of convenience to the beneficiary, reflects the cultural considerations and English proficiency of the beneficiary, includes strategies for resolving conflict or disagreement, offer the beneficiary choices regarding services and providers, includes a process for the beneficiary to request updates to the plan, and records the alternative settings for services considered by the beneficiary.<sup>ci</sup>

The assessment for purposes of drafting the person-centered plan must examine, and the plan reflect, the beneficiary's functional needs, preferences, goals and desired outcomes, and strengths. It must examine the individual's relevant history including medical records, an objective evaluation of functional ability, and any other records or information needed to develop the person-centered service plan, as well as an assessment of the individual's physical, cognitive, and behavioral health care and support needs, strengths and preferences, available housing and service options, and whether unpaid caregivers will be needed. The assessment and subsequent delivery plan must include documentation that no state habilitation service is otherwise available under the Rehabilitation Act or IDEA. Similarly, the assessment must document that services received by the individual under both the State Plan and waiver are not duplicative.<sup>cii</sup>

The written person-centered service plan is required to reflect:

- that the setting in which the individual resides was chosen by the beneficiary and is integrated in, and supports full access of individuals receiving Medicaid HCBS to the greater community, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS;
- the individual's strengths and preferences;
- the clinical and support needs identified through an assessment of functional need;
- individual identified goals and desired outcomes and the services whose purchase or control is to be self-directed;
- risk factors and measures in place to minimize them, including individualized back-up plans and strategies; and
- the services and supports (paid and unpaid) that will assist the individual to achieve identified goals, and the providers of those services and supports, including "natural supports" that are provided voluntarily to the individual in lieu of §1915(c) HCBS waiver services and supports.<sup>ciii</sup>

The person-centered plan must be understandable to the beneficiary receiving services and supports and his support group, written in plain language, and in a manner accessible to an individual with disabilities or limited English proficiency. It must be finalized, with informed consent in writing, and signed by all parties, including providers, responsible for implementation. In addition, it must identify the individual or entity responsible for monitoring the plan.<sup>civ</sup>

All services provided under the person-centered plan must meet medical necessity

criteria.<sup>cv</sup>

## **X. Self-Directed Services**

If a state chooses to permit beneficiaries to self-direct the purchase and control of the duration, scope, location of and provider for HCBS services, and a beneficiary chooses that option, a service plan must be written that:

- specifies the services for which the beneficiary will be responsible;
- identifies the methods by which the beneficiary will plan, direct, or control services, including whether the individual will be responsible for employing service providers or have authority over expenditures from an individualized budget;
- includes appropriate risk-management techniques that explicitly describes roles and how responsibilities will be shared;
- describes any process for facilitating voluntary and involuntary transitions from self-direction, including the circumstances under which transition is to take place and any state procedures for ensuring continuity of care during transition; and
- specifies any financial management supports to manage the beneficiary’s tax, wage-hour, workers’ compensation, insurance, and other obligations as an employer of service providers; and
- provides for the training of the beneficiary in approaches to selecting, managing, and dismissing providers.<sup>cvi</sup>

If the beneficiary has individualized budget authority under the service plan that identifies the dollar value of services and supports under the control and direction of the beneficiary, the plan must describe the method for calculating dollar values in the budget, define a process for making adjustments to dollar values to reflect changes in the service plan, and provide a procedure for evaluating expenditures. Because Medicaid payments cannot be made directly to the beneficiary, the service plan must specify who will carry out financial transactions on the beneficiary’s behalf. It also must provide for the maintenance of separate accounts for the individual’s budget and periodic reports of expenditures in a manner understandable to the beneficiary.<sup>cvi</sup>

## **XI. Quality Improvement Strategy**

States providing HCBS services must develop and implement a Quality Improvement Strategy that includes a continuous quality improvement process and measures of program performance and experience of care. The strategy, which must be provided to CMS when requested, must be—according to the final regulations—“proportionate to the scope of services and the number of individuals served.” The strategy’s required continuous quality improvement process must include monitoring, remediation, and quality improvement. It must be evidence-based, and include outcome measures on program performance, quality of care, and individual experience, providing evidence of

sufficient infrastructure for effective implementation of the program. It also must measure individual outcomes associated with the goals of individual service plans.<sup>cviii</sup>

## **XII. Recommendations**

### **State Agency Level – Using the State Plan Option to Advance HCBS**

- The § 1915(i) State Plan Option and the § 1915(k) CFC option provide more opportunities for developing and financing a greater variety of home- and community-based services in a more specifically targeted manner than ever before. Yet states so far have largely been reluctant to adopt those options. Inpatient services are becoming less favored by federal agencies and members of Congress every day, and continue to face opposition from behavioral health consumer advocates, but the demand for behavioral health services is growing, as is public interest in health care options generated by the publicity around ACA coverage. With demand growing and the financial ability to sustain state inpatient facilities diminishing, states should be exploring now how they can partner with CMS to broaden service options in home- and community-based settings. In doing so, states should keep in mind that SPAs generally require years to develop and CMS approval takes months. However, the approval process time frame can be significantly reduced when a state reaches out early in development to seek CMS input on concepts and structure. States should be reaching out to CMS officials as early and frequently as possible for ideas on how to creatively structure home- and community-based services to maximize federal financial participation.

### **State Agency Level - Community Outreach and Notice**

- CMS is requiring that state transition plans for HCBS be included with submitted §1915(i) and (k) State Plan Amendments and requests for extensions or amendments to existing waivers, and by all states on or before March 16, 2015. Prior to submission to CMS, transition plans must be open to a 30-day public comment, with the public comment period evidenced in transition plan submissions for approval. However, stakeholder input should be solicited long before transition plans are published for public comment. States should reach out to interested stakeholders to help them shape the elements of the required transition plans by identifying potential barriers—such as workforce or service shortages—to accessing their preferred home- and community-based services and providers.

### **Federal Agency Level – Clarity Needed on Non-Residential HCBS**

- As states strive to develop accurate and complete plans for the transition to home- and community-based settings, it becomes ever more critical that the states have a clear picture of what CMS expects with regard to standards for the siting of non-residential services. The guidance setting those standards, promised in January 2014 to be forthcoming, is still pending, with the deadline for state’s initial state transition plans only months away. Transitions will require that existing noncompliant providers be retooled or replaced by new community-based providers, and states will have to at

least generally identify those activities in their transition plans. It is imperative that CMS expedite the promised guidance on non-residential services to provide clarity for states, providers, and beneficiaries working to outline how HCBS will be accessed in the future.

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- i 2 U.S.C. § 12101(a)(2), (3).
- ii 2 U.S.C. §§ 12131 through 12134 (Part A).
- iii 2 U.S.C. § 12182(b)(1)(A).
- iv 28 C.F.R. 35.130(d).
- v 28 CFR pt. 35, App. A, p. 450 (1998).
- vi *Olmstead*, 527 U.S. 581 (1999).
- vii *Ibid*.
- viii 42 U.S.C § 1396n(c).
- ix *Olmstead*, 527 U.S. 581 (1999).
- x 42 U.S.C. § 1396a(a)(1).
- xi 42 U.S.C. § 1396a(a)(10)(B).
- xii Kaiser Family Foundation, Total Number of Medicaid Section 1915(c) Home and Community-Based Services Waivers (updated May 27, 2014), <http://kff.org/medicaid/state-indicator/total-number-of-medicicaid-section-1915c-home-and-community-based-services-waivers/>.
- xiii <http://www.medicicaid.gov/Medicicaid-CHIP-Program-Information/By-Topics/Waivers/dynamic-list/WA-508.xml>.
- xiv P.L. 109-171 (Feb. 8, 2006).
- xv 42 U.S.C. § 1396n(i).
- xvi 79 Federal Register 2948, 2951 (January 16, 2014).
- xvii State Medicaid Director Letter (SMDL) #10-015 (August 6, 2010).
- xviii *Ibid*.
- xix 42 U.S.C. § 1396n(k).
- xx Basic Activities of Daily Living include eating/feeding (including chewing and swallowing), toileting, grooming, dressing, functional mobility, and bathing/showering.
- xxi Instrumental Activities of Daily Living include meal planning and preparation, managing finances, light housework, and transportation; and health-related tasks, such as tube feedings, catheterization, range of motion exercises and medication administration.
- xxii Health-related tasks include tube feedings, catheterization, range of motion exercises, and medication administration.
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- xxv 79 Federal Register 2948 (January 16, 2014).
- xxvi *Ibid*, 2969, 3031.
- xxvii *Ibid*, 2968.
- xxviii 29 U.S.C. § 794(a), Pub.L. 93-112 (September 26, 1972).
- xxix 45 CFR 84.4, 42 Federal Register 22677 (May 4, 1977).
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- xxxvi 35 C.F.R. 35.130(b).
- xxxvii 28 C.F.R. 35.130(d).
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- <sup>1</sup> *Ibid.*
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- lxvii Instrumental Activities of Daily Living include meal planning and preparation, managing finances, light housework, and transportation; and health-related tasks, such as tube feedings, catheterization, range of motion exercises and medication administration.
- lxviii Health-related tasks include tube feedings, catheterization, range of motion exercises, and medication administration.
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- civ *Ibid*.
- cv *Ibid*, 3038, 42 CFR 441.745.
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