Before the
UNITED STATES DEPARTMENT OF HEALTH & HUMAN SERVICES
CENTERS FOR MEDICARE & MEDICAID SERVICES

In the Matter of	)
	)
Proposed Medicaid Program Rules on	)
	)
HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVERS	)
	)
CMS-2296-P	)
	)

JOINT COMMENTS OF FOURTEEN STATE MEDICAID AGENCIES

The agencies and officials responsible for administering the Medicaid program in Alaska, California, Hawaii, Illinois, Louisiana, Maine, Maryland, Michigan, Missouri, Nevada, Rhode Island, Tennessee, Washington, and Wisconsin ("the Commenting States") submit the following comments on the proposed rule regarding Section 1915(c) waivers published by the Centers for Medicare & Medicaid Services ("CMS"). *See* 76 Fed. Reg. 21,311 (Apr. 15, 2011).[*]

Proposed Section 441.301(b)(1)(iv) imposes new restrictions on the types of residential settings open to recipients of home- and community-based services ("HCBS") through a Section 1915(c) waiver. The proposed rule includes three categorical prohibitions, denying recipients the option of living (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." *Id.* at 21,317. The

[*] Several of the Commenting States are submitting individual comments as well.

proposed rule also gives the Secretary discretion to deem any other setting inappropriate for waiver recipients because it "[h]as qualities of an institutional setting." *Id.*

The apparent intent of the rule is to promote integrated community-living settings. The Commenting States support that goal but believe the proposed rule significantly misses the mark. Based on their collective experience, the Commenting States believe that Proposed Section 441.301(b)(1)(iv) is likely to limit recipients' choices without meaningfully advancing the goal of community integration. Because the States doubt the proposed rule's ability to achieve its apparent purpose and because there are serious concerns about negative effects the proposed rule might have on Medicaid recipients, the Commenting States object to this aspect of CMS's proposal.

These comments first explain why the Commenting States believe Proposed Section 441.301(b)(1)(iv) should be excluded from the final rule. If CMS proceeds with its plans to codify this provision, the Commenting States believe the rule requires substantial revision and clarification, as discussed below.

A. General Comments

As a general matter, Proposed Section 441.301(b)(1)(iv) requires that Section 1915(c) waiver services be provided "[o]nly in settings that are home and community based, integrated in the community, provide meaningful access to the community and community activities, and choice about providers, individuals with whom to interact, and daily life activities." 76 Fed. Reg. at 21,317. The proposed rule then establishes four categories of settings that are "not integrated in the community" and therefore inappropriate for waiver recipients. *Id.*

The Commenting States do not think Section 1915(c) is best read to mandate a dichotomy between settings that are "integrated in the community" and those that are not. The use of these binary categories does not appropriately reflect the fact that the diverse populations served by the Medicaid program require a continuum of assistance. Many individuals are able to live comfortably in their own, free-standing homes with the services offered through an HCBS waiver, while some may be unable to take advantage of waiver services because no non-institutional setting will be appropriate. In the middle is a diverse group of individuals who prefer, or are otherwise best served in, congregate and/or assisted-living settings that offer the supports necessary to allow them to avoid settings with stronger institutional features.

The Commenting States are concerned that, for some individuals in this last group, the most desirable alternative to placement in a nursing home or ICF/MR may be a setting that the proposed rule classifies as "not integrated in the community." Under the proposed rule, these individuals would be denied access to waiver services and may be left with no choice but to reside in a less integrated, more institutional setting. We do not believe that denying some Medicaid beneficiaries the opportunity to live in the most integrated setting appropriate to their needs and consistent with their desires effectuates the purposes of Section 1915(c).

The problem is compounded by the fact that the proposed rule entirely fails to acknowledge the existence of at least one group of beneficiaries: individuals who currently receive Section 1915(c) waiver services but live in a setting that will no longer qualify as "home and community based" or "integrated in the community." The proposed rule does not appear to take the interests of this group into account. CMS should not adopt a rule that will force these individuals into an institutional setting or require them to leave their current homes. The proposed rule does not even begin to suggest how CMS and the States will address the

potentially unsettling consequences of CMS's current thinking for this group of current Section 1915(c) waiver recipients.

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 Section 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.

A balance must be struck between offering independence and providing needed support. The Commenting States are concerned that the proposed rule does not strike the right balance. The only limitation recognized in Section 1915(c) is that waiver recipients may not reside in a nursing home or ICF/MR. We feel that CMS should not use the rulemaking process to prevent individuals from receiving needed services solely because their place of residence falls within one of the artificial categories contained in the proposed rule, particularly when those

services would support those individuals moving from more restrictive to more individualized living arrangements. Individuals in waiver programs are paying for room and board out of their own pockets, and subject to overriding safety or medical concerns, they should be free to select a residential setting without regard to the limitations contained in the proposed rule. Recipients, not CMS, should be allowed to choose the residential setting most appropriate for them.

The Commenting States believe 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. In light of this concern, the Commenting States oppose the inclusion in the final rule of Proposed Sections 441.301(b)(1)(iv) and 441.302(a)(5).

B. Comments on Specific Provisions of the Proposed Rule on HCBS Settings

If CMS does proceed with its plans to codify categories of settings that are "not integrated in the community," the Commenting States urge CMS to adopt the following revisions and clarifications to the proposed rule.

1. The Prohibition on Waiver Recipients Living in Residences "on the Grounds of" or "Immediately Adjacent to" a Public Institution Is Overly Prescriptive.

Proposed Section 441.301(b)(1)(iv)(A) denies HCBS waiver recipients the option of living "in a building on the grounds of, or immediately adjacent to, a public institution." 76 Fed. Reg. at 21,317. The preamble, however, would impose an even broader prohibition. It states that HCBS settings may not include "a building on the grounds of, or immediately adjacent to, a public or private institution." *Id.* at 21,314. The Commenting States believe the proposed

rule is overly prescriptive in its current form and would be only more so if extended to buildings on the grounds of, or immediately adjacent to, private institutions as well as public institutions.

a) Proximity to a Hospital or Other Institution Is Desirable to Many Elderly Persons and Individuals with Adult-Onset Disabilities and Should Not Be Denied to Waiver Recipients.

The proposed rule denies Medicaid beneficiaries the opportunity to live in otherwise desirable assisted living settings based solely on their proximity to a hospital or nursing home. This is so even if the residence satisfies all of the other criteria that make assisted living settings appropriate for HCBS recipients. That means that Section 1915(c) beneficiaries cannot live in a residence that offers individual living, apartment-style units, lockable access to individual apartments, unrestricted ability to leave the residence, unrestricted ability to invite visitors, aging in place, and easy access to the greater community based on each resident's needs and preferences, 76 Fed. Reg. at 21,313—just because that residence is in a building on the grounds of, or immediately adjacent to, a hospital or nursing facility.

This provision is overly prescriptive, and it would eliminate residential options that are attractive to many individuals with disabilities, particularly those who are also elderly. Under the final rule, an assisted living setting or continuing care retirement community that satisfies the "conditions" necessary for it to qualify as "permissible under the section 1915(c) HCBS program," *id.*, should not be disqualified simply because it is in a building that is on the grounds of, or immediately adjacent to, a hospital or other institution. The broad restriction contained in the proposed rule will deny many Medicaid beneficiaries (and particularly those who are elderly) the opportunity to receive necessary services in a setting that appropriately helps maximize their independence.

The Commenting States do not believe that the proposed policy will advance the goal of independent living for the elderly and individuals with adult-onset disabilities. Indeed, proximity to a hospital or nursing home can promote independence. For many elderly individuals—whether or not they have a disability and whether or not they receive Medicaid benefits—residing in close proximity to a hospital or nursing home facilitates aging in place. A residence's proximity to these institutions allows elderly individuals to receive necessary emergency care, rehabilitation, and other services with minimal disruption to their daily lives. This is why such settings are desirable to many aging individuals regardless of their Medicaid eligibility.

The Department of Health and Human Services ("HHS") has in fact recognized the many benefits associated with the type of setting that the proposed rule would deny to Section 1915(c) waiver recipients. HHS has reported, for instance, that many high quality Adult Residential Care providers nationwide are located within, or on the same campus as, nursing homes. *See* U.S. Dep't of Health & Human Services, *High Service or High Privacy Assisted Living Facilities, Their Residents and Staff: Results from a National Survey*, at 49 (Nov. 2000) (finding that, in a nationwide study of nearly 1,500 assisted living facilities, almost two-thirds (64%) of not-for-profit assisted living facilities were located on a multi-level campus with other types of supportive housing for the elderly, including nursing homes). HHS has further recognized that such providers can be an attractive option to eligible individuals because they can offer residents all forms of care necessary through the continuum of care available on-site. *See* U.S. Dep't of Health & Human Services, *Continuing Care Retirement Communities*, at 23 (Feb. 1997) (describing the benefits of continuing care retirement communities, which offer stages of care including independent living, assisted living, and skilled nursing care). As a

result, assisted living facilities on multi-level campuses tend to have higher occupancy rates and provide more services for residents than do freestanding assisted living facilities. *See* U.S. Dep't of Health & Human Services, *A National Study of Assisted Living for the Frail Elderly: Final Summary Report*, at 14 (Nov. 2000).

Particularly in light of HHS's past recognition of the benefits to the elderly and individuals with adult-onset disabilities of living "on the grounds of, or immediately adjacent to," an institution, the Commenting States understand that CMS may not have had these populations in mind when it prepared the proposed rule. Indeed, the preamble suggests that CMS primarily disapproves of "congregate settings [for HCBS waiver recipients that] are being planned on the grounds of existing Intermediate Care Facilities for Individuals with Mental Retardation (ICF/MRs)." 76 Fed. Reg. at 21,312. There are, by contrast, good reasons to allow HCBS programs targeted at the elderly and individuals with adult-onset disabilities to offer recipients the option of living in a residence on the grounds of, or immediately adjacent to, a nursing home or other institution. The final rule should either eliminate this provision from Section 441.301(b)(1)(iv) or should specify that the provision does not apply to residences that target the elderly or individuals with adult-onset disabilities.

b) The Proposed Rule Should Not Be Extended to Cover Private Institutions.

As the Commenting States read the proposed rule, a building on the grounds of, or immediately adjacent to, a private institution may be an appropriate HCBS setting so long as it is not located in the same building as the institution. Any final rule should preserve this limitation. Moreover, CMS should not treat all buildings on the grounds of, or immediately adjacent to, a

private institution as having "qualities of an institutional setting" under Proposed Section 441.301(b)(1)(iv)(B).

The above reasons for omitting or narrowing the provision regarding settings "on the grounds of, or immediately adjacent to, a public institution" apply with at least equal force to private institutions. But there are also additional reasons why the proposed rule should not be extended to cover private institutions.

It is widely recognized among stakeholders that reducing institutional capacity is an important part of States' efforts to rebalance their long-term care programs in favor of HCBS. States that have traditionally relied on private, rather than public, institutions to serve their Medicaid population have found it difficult to reduce institutional capacity without giving their institutional providers incentives to draw down their capacity. In the past, state Medicaid programs have successfully encouraged providers to convert part of their institutional capacity into assisted living settings that are on the grounds of, or immediately adjacent to, the institution.

If the final rule applies to settings "on the grounds of, or immediately adjacent to, a private institution," the rule will deny many residents of converted assisted living settings the opportunity to receive Medicaid-funded services while hindering States' efforts to promote HCBS by reducing existing institutional capacity. For the reasons discussed above, the proposed rule is itself overly broad. But, in any event, the final rule should not be made any more restrictive by extending it to cover private institutions.

2. CMS Should Not Adopt a Rule Barring Waiver Recipients from Living in Settings Designed Around Diagnoses or Disabilities.

Section 441.301(b)(1)(iv)(A) of the proposed rule treats any "housing complex designed expressly around an individual's diagnosis or disability" as insufficiently integrated in the community for recipients of HCBS waiver services. As with the provision discussed above, this provision appears to prevent Section 1915(c) waiver recipients from living in a building that offers individual living, apartment-style units, lockable access to individual apartments, unrestricted ability to leave the residence, unrestricted ability to invite visitors, and easy access to the greater community based on each resident's needs and preferences—for no other reason than because the building is "designed expressly around an individual's diagnosis or disability."

The proposed rule will not only deny Medicaid beneficiaries the opportunity to live in an otherwise desirable residence that lacks the features of an institutional setting, it will also undermine efforts by other branches of the federal government to expand housing opportunities for low-income individuals with disabilities. For instance, the Department of Housing and Urban Development ("HUD") provides financing for housing complexes designed expressly around an individual's diagnosis or disability under Section 811 of the National Affordable Housing Act of 1990. According to HUD, "[t]he purpose of the Section 811 program is to enable persons with disabilities to live with dignity and independence within their communities by expanding the supply of housing that provides supportive services which address the individual health, mental health and other needs of the residents and is designed to accommodate these special needs." HUD Handbook 4571.2, at §1-3, *available at* http://www.hud.gov/offices/adm/hudclips/handbooks/hsgh/4571.2/45712c1HSGH.pdf.

States have relied on Section 811 funding to offer individuals with disabilities residential options that, while designed around individuals' diagnosis or disability, are fully integrated in the larger community. California, for example, has recently opened new affordable housing units for individuals with developmental disabilities in San Francisco. House Minority Leader Nancy Pelosi attended the opening of one such residence and declared that it should serve as a model for similar affordable housing units across the country. *See* Congresswoman Pelosi Joins Mayor Lee, Supervisor Mar for Opening of St. Peter's Place Affordable Housing, *available at* http://richmondsfblog.com/2011/04/25/congresswoman-pelosi-joins-mayor-lee-supervisor-mar-for-opening-of-st-peters-place-affordable-housing. By prohibiting HCBS waiver recipients from choosing to live in residences designed around their diagnosis or disability, the proposed rule appears to deny recipients the opportunity to live in such model residences and to interfere with other federal programs intended to promote independent living for individuals with disabilities.

As with the other categorical prohibitions in the proposed rule, this provision deprives waiver recipients of attractive residential options in settings that are wholly integrated in the community and significantly less restrictive than an ICF/MR. For many potential residents, the alternatives might be limited to more institution-like settings and/or non-institutional settings that the individuals consider less likely to meet their needs. Because the Commenting States favor preserving and expanding the choices currently available to HCBS waiver recipients, we oppose any categorical rule that would deny them the opportunity to reside in a setting that is designed to meet the needs of individuals with their particular diagnosis or disability.

3. All Waiver Recipients Should Be Permitted to Choose to Live in Assisted Living Facilities.

Although the subject is not explicitly addressed in the text of the proposed regulation, the preamble to the proposed rule states that, "under certain circumstances," assisted living facilities are "permissible under the section 1915(c) HCBS program for older persons." 76 Fed. Reg. at 21,313. The preamble recognizes that an assisted living facility is often the preferred residence for "persons who are older with and without disabilities," *id.*, and the proposed rule appropriately "allow[s] them to exercise this preference and receive waiver services," *id.*

The Commenting States feel that all persons with disabilities should be allowed the same choice. Younger individuals with disabilities should be permitted to choose to live in assisted living facilities and receive the same HCBS that the proposed rule allows elderly individuals to receive. For many persons with disabilities—regardless of their age—assisted living settings are the surest way to ensure that they receive the services they need either to move out of an institution or to avoid the need for institutional care in the first place. Medicaid recipients should not be denied access to such a valuable service on the basis of age.

Allowing all individuals with disabilities to preference assisted living settings will also advance the purpose behind Proposed Section 441.301(b)(6). That section would allow States to combine the three existing waiver target groups (the aged and/or disabled; individuals with intellectual and/or developmental disabilities; and the mentally ill). The Commenting States believe that waivers open to multiple target groups may be more difficult to administer if assisted living settings are permissible for some target groups but not others. Moreover, as noted in the preamble, the proposed amendment will allow "individuals with intellectual disabilities

[to] reside with aging caregivers who are also eligible for Medicaid." *Id.* at 21,312. If assisted living facilities are off-limits for younger recipients, however, those individuals may be denied access to the setting best able to meet their needs while allowing them to reside together. The Commenting States therefore feel that assisted living facilities should be no less open to younger individuals with disabilities than they are to older individuals.

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For the reasons discussed above, the Commenting States oppose the incorporation of Proposed Sections 441.301(b)(1)(iv) and 441.302(a)(5) in the final rule. These provisions, though well intentioned, are not likely to have the desired effect. In any event, the proposed rule requires significant revisions and clarifications in order to avoid having a substantial negative impact on some Medicaid beneficiaries.

Respectfully submitted,

/s/

Charles A. Miller
Caroline M. Brown
Matthew J. Berns
Covington & Burling LLP
1201 Pennsylvania Avenue, N.W.
Washington, DC 20004-2401
(202) 662-5410

On behalf of the Commenting States

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