



June 14, 2011

Via: Electronic Mail

The Honorable Don Berwick
Administrator
Centers for Medicare and Medicaid Services
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

**Re: File Code CMS-22996-P
Proposed Rule for Home and Community-Based Services Waivers (HCBS)**

Dear Administrator Berwick:

Thank you for the opportunity to comment on the proposed rule for the Medicaid Program Home and Community-Based Services Waivers, as published in the Federal Register, 76:73 on Friday, April 15. The Disability Rights Education and Defense Fund (DREDF) is a leading national law and policy center that advances the civil and human rights of people with disabilities through legal advocacy, training, education, and public policy and legislative development. We are a cross-disability organization, and are submitting this letter to support comments submitted earlier this month by the Bazelon Center for Mental Health Law, a national legal-advocacy organization founded in 1972 and representing people with mental disabilities.

Target Groups, Section 441.301 (b)(6)

We strongly support the change that will permit states to combine targeted groups within one waiver. For example, there are frequently similarities in service needs for persons with mental illness and persons with developmental disabilities. Further, the co-occurrence of serious physical illness and disability among those diagnosed with mental illness is well-documented. Combining targeted groups is thus consistent with the “person-centered” process embraced by this rule, encouraging the provision of services that are based on individual need rather than diagnosis or age. We agree also that the protections CMS has included in this rule are critical for ensuring that each individual who receives waiver services through such a combined waiver will have equal access to the services necessary to meet their unique needs. It has long been of concern to the Center that only a very few states have applied for waivers for adults with mental illness, despite the fact that the waivers are available for individuals who might otherwise be institutionalized in a nursing facility or, for those over age 64 in states with the option, in a psychiatric hospital.

Creating an option for states to combine disability categories should reduce the existing disparity with respect to waiver services between people with mental illness and those with other disabilities and enable states to focus on serving people with the greatest needs. We believe this change would lead to greater compliance with the Americans with Disabilities Act

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as it would enable more people with serious mental illness to move out of nursing facilities and psychiatric hospitals or avoid such admissions altogether.

We urge CMS to clarify the requirement that states choosing to serve multiple target groups in a single waiver must “meet the unique service needs” of each individual in each target group. Persons with mental illness have historically been almost entirely excluded from nursing facility waivers because these waivers generally do not cover the array of services this group requires. Waivers serving multiple target groups should be required to cover an array of services specifically needed by each of the covered groups (such as personal care assistance for some and skills training for others) as well as generic services that will benefit all (such as respite care), and this should be spelled out in the waiver application.

We recommend that the requirements that “States must assure CMS that they are able to meet the unique service needs that each individual may have regardless of target group, and that each individual in the waiver has equal access to all needed services” and that waivers serving multiple target groups must cover an array of services specifically needed by each of the covered groups, be included in the regulation itself and not solely in the Preamble.

We also urge that cost neutrality for these combined waivers not be calculated separately for each of the population groups that the waiver might serve. This should be included in this regulation, not left for a new notice on cost neutrality to be issued later.

Recommendation: We urge CMS to retain these changes to Section 441.301(b)(6) as proposed. Waivers serving multiple target groups should be required to cover an array of services specifically needed by each of the covered groups, and this should be spelled out in the waiver application. In addition, the language cited above from the Preamble should be included in the final regulation. We urge that cost neutrality for these combined waivers not be calculated separately for each of the population groups that the waiver might serve. This should be included in this regulation, not left for a new notice on cost neutrality to be issued later.

HCBS Settings: Section 441.301(b)(1)(iv)

The proposed rule would require that HCBS settings must be integrated in the community, must not be located in a building that is also a publicly or privately operated facility that provides institutional treatment or custodial care, must not be located on the grounds of, or adjacent to, a public institution, and must not be a housing complex designed expressly around an individual’s specific diagnosis or disability. These are excellent protections that should be retained since they are critical in providing needed clarity about what the term “home and community based” means. This will ensure that limited H&CB service funds are not expended on congregate settings that are institutional in nature. The rule should clarify that the funds may not be expended on services that are delivered in segregated settings, including non-residential settings. Thus, the waiver should not fund services in sheltered workshops or other congregate settings created solely for people with **disabilities that do not directly further the goals of community integration and choice.**

The new rule will appropriately provide impetus for supportive housing arrangements that give people both immediate, permanent housing in their own apartments or homes and access to voluntary, supportive, H&CB services designed by the individual and provider to ensure success.

The rule proposes excluding settings that provide “custodial care.” The term “custodial care” is sometimes defined to include personal care assistance with activities of daily living, and we do not believe that the Department intends to increase the difficulty of obtaining such services. We recommend that the rule clarify the availability of waiver funds for personal care assistance when it is voluntarily received in a setting that meets the rule’s integrated setting criteria. We agree that custodial care, provided in an institutional setting, should not qualify for funds available under an HCBS waiver.

CMS should also clarify that H&CB service funds generally cannot be used for congregate settings, where people typically have little control over many aspects of their daily lives. Frequently, Medicaid is billed for services to individuals who reside in facilities sized so as to just avoid meeting the CMS definition of an IMD (i.e., they have 14 or 15 beds). These facilities generally have the characteristics of an institution. Some are located on or adjacent to state mental hospitals.

We urge that the rule specify that H&CB service funds may not be used to fund services in congregate settings except where small groups of persons with disabilities choose to live together and where the setting does not have the qualities of an institution, as listed in this section. The rule should also forbid states from using HCBS waiver funds to provide services to individuals living in a setting in which they are required to receive and participate in services as a condition of continued tenancy. CMS should review state applications to ensure that these standards are met.

The NPRM lists the qualities of an institution (regimented meal and sleep times, limitations on visitors, lack of privacy, and other attributes that limit an individual’s ability to engage freely in the community). This list is extremely important. It defines settings that do not meet the definition of “community-based” and should be included in the regulation itself, in order to provide states with a clear understanding of settings that are institutional and to ensure compliance with the rule. The regulation should also note that generally these limitations will not be present in settings that meet the “location” requirements in Section 441.301(b)(iv)(A). The regulation should specify that a “housing complex designed expressly around an individual’s diagnosis or disability” includes complexes that serve individuals with different diagnoses or disabilities and not just complexes that serve individuals with a particular diagnosis or disability. This includes Section 202 and 811 housing projects that serve people with disabilities, or people with disabilities and older adults.

Assisted Living Facilities

There is no basis in the statute to have different rules for assisted living facilities than for any other setting. These programs should be subject to the restrictions outlined in this rule. In the

Background section, CMS suggests that ALFs might be carved out as an exception. This is misguided and contrary to Congressional intent. ALFs are congregate settings. In some states, these facilities are little different from nursing facilities that house individuals of all ages. Permitting scarce waiver funds to be directed to these facilities would not enhance consumer choice, but would instead deprive individuals of the choice to live in community settings. Seniors with disabilities, like their younger counterparts, would prefer to live in homes of their own choice, with the supports (and any roommates) that they choose, delivered in the manner that allows them to live their lives as fully as possible.

We understand that some groups have expressed concerns about eliminating HCBS waiver funding for ALF's, as they have become part of the housing inventory for seniors around the country. However, HCBS waiver funds are not an appropriate source of funding for this type of housing, especially since States can use other Medicaid resources to serve individuals in ALF's. For example, relevant services can be funded under the state options of Rehabilitation and Targeted Case Management.

In this proposed rule, CMS has not stipulated an upper limit on the number of beds allowed for a placement to be considered suitable under a HCBS waiver. Facilities with 8, 10 or 14 residents are, by nature, institutional in many ways. We urge that no HCBS waiver setting should have more than three to four bedrooms. Additionally, a setting with two or more beds, in order to qualify as an integrated (HCBS waiver) setting, must be one in which individuals with disabilities have chosen to live together and which does not have the qualities of an institution.

Recommendation: We urge that CMS retain the proposed rule regarding placement of waiver settings but that additional requirements regarding the size and characteristics of the setting be incorporated into the rule.

Person Centered Planning

Section 441.301(b)(1)(i)(B)(3), regarding the Person-Centered Plan and the individual's goals, should refer to "health and mental health" care and also recreation and socialization, and other supports needed to enable Medicaid recipients to live independently in the community setting of their choice. We applaud the rule for focusing the delivery of services on "person centered care" and "planning processes." This focus represents an effective application of the civil rights mandates to the Medicaid program.

Strategies to Ensure Compliance with Statutory Assurances

The Department proposes adding compliance strategies to its enforcement mechanisms. The strategies include the imposition of a moratorium on waiver enrollments and withholding full funding for waiver services or the administration of waiver services. We encourage the Department to apply these new mechanisms. Enforcement tied to funding has proved to be the most efficient and effective means of correcting prohibited practices, not just in HHS programs, but in programs operated by HUD, DOT, and the Department of Education as well. Slowing the flow of Federal funds gives the Medicaid agency programmatic and political opportunities to alter traditional practices and adopt new service delivery approaches. It also gives both the

Department and the state agency technical assistance opportunities. These opportunities become especially important during difficult economic downturns when training, staff support, and staff positions are often the first items to be deleted from budgets, leading to practices that skirt and sometimes violate compliance obligations.

Yours Truly,

A handwritten signature in blue ink that reads "Susan R. Henderson" followed by a horizontal line.

Susan R. Henderson
Executive Director