

July 2, 2012

Via online submission at www.regulations.gov

Marilyn Tavenner
Acting Administrator
Centers for Medicare and Medicaid Services
Department of Health and Human Services
Attention: CMS-2249-P2
P.O. Box 8016
Baltimore, MD 21244-8016

**Re: Comments on Proposed Rule for State Plan HCBS;
77 Fed. Reg. 26362 (May 3, 2012)**

Dear Administrator Tavenner:

Thank you for the opportunity to comment on the above-proposed rule concerning the Section 1915(i) State Option to provide home and community-based services (HCBS) for Medicaid-eligible individuals. 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 believe the state option has great potential to provide people with disabilities, including those disabilities that remain highly stigmatized in the public eye such as mental illness, with the opportunity to obtain a wide range of necessary services and supports while remaining in, and returning to, homes in the community. This potential can only be fully realized, however, if the rule provides states and providers with strong and unequivocal guidance regarding the need to offer, develop, and provide chronic care services in the most integrated settings possible.

DREDF has read and agrees with both the overarching and more specific comments of our colleagues at both the Bazelon Center for Mental Health Law and the National Disability Rights Network concerning the proposed Rule. Our chief concerns and recommendations are as follows:

- Individuals cannot have access to their current or potential housing conditional upon the receipt of any particular service, treatment, or support. The right to refuse a service is a fundamental right of people with and without disabilities, and any setting that receives public funding as “community-based” must be prohibited from evicting an individual, or refusing to consider an individual housing application, from someone who refuses to accept a particular service. This accords not only with human rights, but also evidence concerning the lower treatment efficacy of programs that condition housing upon treatment and take away choice and volition from individuals with disabilities, including those with psychiatric disabilities, substance abuse impairments, and dual diagnoses.

- The exception that allows provider-owned or controlled residential settings to depart from the qualities otherwise required of home and community-based settings (§§ 441.656(a)(1)(vi) and 441.530(a)(1)(vi)) is potentially far too broad. The Rule should clarify that certain aspects of HCB settings, such as choosing one's unit-mate or choosing one's furnishings/decorations or choosing who can visit when, are so commonly inherent in having one's own "home" that they cannot be consistently or typically circumscribed for any reason, without the setting losing its status as a "community" setting. In those extremely exceptional circumstances where an individual may require very specific "additional conditions" that limit individual choice (e.g., eliminating the ability of a person with dementia to fully and independently lock doors to and within their unit because of the risk of self-endangerment), there must be clearer requirements relating to the how such restriction are tailored as narrowly as possible to the needs of the person with a disability. Otherwise, it is *much* too easy to just impose restrictions convenient to the needs of the provider (e.g., taking away the use of a power wheelchair because an individual smokes in inappropriate places, leaving the individual without mobility and virtually bound to his or her bed). Such requirements and carefully enumerated examples must be provided so that providers and developers get the serious message that entire facilities or departments cannot be built or established with conditions or treatments attached to the housing because of broadly assessed needs, documented in outmoded service plans built around individuals (or individual's family) that were not presented with the most integrated options.
- The creation of a rebuttable presumption that a setting is not a HCB setting makes sense in light of a long-held historic funding bias toward institutional long-term services and supports and community segregation for people with disabilities and chronic care needs, but as written may not be robust enough. There continue to be strong economic incentives for states, local government authorities, and providers to work together on bundling housing and services very close to former or existing segregated institutional locations; once an institution is built, the incentives fall toward keeping that institution and property "fully" utilized. These incentives will not be easily overcome, and may well require an outright prohibition on providing public funding to settings that share the buildings or grounds of an institution that provides in-patient care.

DREDF also acknowledges that advocacy organizations such as National Senior Citizen's Law Center (NSCLC) and National Center on Aging (NCOA) have made numerous particular suggestions that we support and would, in fact, further expand. For example, with regard to § 441.665, NSCLC recommends "adding a requirement that the process "is physically and linguistically accessible to the individual." DREDF endorses the wisdom of making accessibility explicit and not just implicit in the concept of person-centered planning, and would include the requirement that all documentation and procedural requirements in the person-centered process be made accessible to people with functional impairments. Many individuals with visual or print-related processing impairments can verbally and linguistically interact with service providers in a person-centered process, but cannot be expected to retain all the details of the verbal

conversation if the notes, final plan, and revisions are not made available as a permanent and accessible record in Braille, electronic, large-font print, or audio format.

On the other hand, we cannot fully endorse the suggestions of many senior advocacy groups that seek a softening of the Rule's language around settings that are not home and community-based (§§ 441.656(a)(2)(iv) and 441.530(a)(2)(iv)) and characteristics that give rise to a rebuttable presumption that a setting is not home and community-based (§§ 441.656(a)(2)(v) and 441.530(a)(2)(v)). DREDF appreciates that these advocacy organizations are legitimately reflecting the voices of their constituents, including seniors who are attracted to settings that provide multiple levels of care, rising up to inpatient institutional care, on the same grounds or in the same building.

However, DREDF strongly advocates that this Rule must curtail or abolish, as much as possible, the old cycle of assumptions that people with chronic and complex medical conditions can only be properly cared for in nursing facilities, leading to "if we build it they will come" consequences. Ultimately, providers and developers must be required to avoid fitting patients into a program and facility, and encouraged to take innovative steps to – *if* they want public funding – shape their programs and facilities to the most integrated options that the great majority of people with disabilities of all ages desire and can benefit from. Our difficulties with some of the suggestions of our senior advocacy colleagues include the following concerns:

- They reward a kind of expansion of institutions, with housing arrangements that encourage spouses and family members to tie their own housing to the institutional housing of the family member who requires the most care, rather than encouraging the development of innovative solutions for how individuals with various chronic and high care needs may be housed in the most integrated settings.
- It is inherently easier for providers to cater to and assuage the fears of seniors who are acquiring unfamiliar impairments than to educate and empower them and their families regarding the full range of inclusive housing and service options, including the most integrated settings. While there is *no* wish to force any individual to take on the risks and choices of a community option that they genuinely do not wish to have, there is a larger structural need to ensure as much as possible that individuals who are unfamiliar with the full range of their options are informed about and helped to navigate those options, as well as the quality of life that is enjoyed and prized by peers of a similar age who have lived with similar or more complex impairment levels for longer periods of time.
- While it is tempting to cleanly differentiate between the needs and wishes of seniors constituents and the disability community regarding the Rule, this does not take into account the increasing numbers of people with disabilities who are aging, in large part due to medical improvements and research discoveries. This is a group that keenly holds to the principles of independent living and wish to preserve their hard-fought lives in the community, and also a group that represents an income level that, on average, is most likely to require publicly-funded HCB settings. These are individuals who must be assured that, as

seniors, they will not have any weaker protections around, or incentives for, gaining access to services and supports in a truly integrated community setting. Providers who seek public funding do not generally provide the more “layered” levels of care and nuanced living arrangements that private pay providers can offer, but they can seek to emulate such arrangements. The Rule must ensure that community settings do not merely meet surface indicia, but are a “home in the community” in the most profound sense.

Thank you again for the opportunity to comment on a regulatory package that is of such central importance to people with disabilities of all ages, in all of our communities.

Yours truly,

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

Susan Henderson,
Executive Director