

May 30, 2011

Mr. Barack Obama  
President of the United States of America  
The White House  
1600 Pennsylvania Avenue, N.W.  
Washington, D.C. 20500

re: Proposed CMS Regulation CMS-2296-P (<http://www.gpo.gov/fdsys/pkg/FR-2011-04-15/pdf/2011-9116.pdf>)

Dear Mr. President:

On behalf of Florida's Voice on Developmental Disabilities, a Florida 501(c)(3) non-profit comprised of families and friends of persons with developmental disabilities, I write you to comment regarding proposed regulations by CMS (CMS-2296-P) which would negatively redefine eligibility for Medicaid home & community based services (HCBS) based on their definition of an "HCBS Setting."

There are 3 substantive changes proposed:

**First**, there is an expansion of the "target group" wherein target groups may be combined. The example given would be combining an individual with intellectual disabilities who resides with aging caregivers, and wherein all might be eligible for Medicaid. The proposal would have both serve under the same waiver program, and , states would be able to design a coordinated section 1915 (c) waiver structure to accomplish this objective and obviate the need for two waiver slots. We have no objection to this proposed change.

**Second**, the defined "settings" which would allow for eligibility for the HCBS program is specifically the proposal that we find highly **objectionable**. HCBS would not be allowed in any "segregated setting(s) with a strong institutional nature." The proposal would not allow for HCBS services on a "campus-based segregated setting," whether "on the grounds of existing Intermediate Care facilities for Individuals with Mental Retardation (ICF/MRs), or, in other segregated settings." Then the proposed reg attempts to describe such "segregated" settings in an extremely restrictive fashion, thereby eliminating residential options for many families. The **term "segregated" is inflammatory** in its own right, and implies that an individual is being - against their will - kept from the rest of the community. The only exception would be, essentially, assisted living facilities for seniors, and tribal lands for American Indians & Alaska Natives.

The reg states that the setting "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 in a building on the grounds of, or immediately adjacent to, a public institution; or, must not be a housing complex designed expressly around an individual's diagnosis or disability, as determined by the Secretary.....the settings must not have qualities of an institution, as determined by the Secretary.....Such qualities may include regimented meal and sleep times, limitations on visitors, lack of privacy and other attributes that limit individual's ability to engage freely in the community." "Disability-specific housing" is also deemed "segregated."

How would we then define private senior retirement communities - as "segregated?" People choose to live in such large communities, and the disability community should enjoy the same freedoms without the pejorative tag "segregated" attached to their choice of a residential option.

Although some individuals with developmental disabilities who are medically fragile may require a larger residential setting (e.g., an ICF/MR), the vast majority of persons with developmental disabilities do not require a medical model, and can be on the HCBS Medicaid waiver in a non-medical setting.

Many families have elected to keep their loved one at home, others have selected independent living w/ supported living coaches, others have selected small group homes, and others have concluded that a large, private "planned residential community" may be in their family member's best interest.

The proposed definition of "segregated" settings is very offensive, and eliminates the variety of residential choices from families, including large, private planned residential communities.

The regs rely in part on the Olmstead decision (U.S. Supreme Court, 1999) which simply stated that when an individual does not want to remain in an institutional setting, and the professionals agree with the individual, and the State has the funding, the individual should be placed in a community setting. However, Justice Ginsberg clearly stated,

"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings."

These proposed regulations would disallow individuals in larger, private communities from living there because the regulations deem a home in such a community as a "segregated" setting. Nothing could be further from the truth! Many individuals in single family homes strewn throughout communities are socially isolated from their neighbors. Most group homes are run with rules in place which parallel what those of us living in "typical" households consider reasonable - established meal times, etc.

The proposed regulations re-defining HCBS Settings is offensive and needs to be removed as currently drafted.

**Third**, the regulations speak about "person-centered planning," a nice concept that has been misused to promote various political agendas, such as the "HCBS Setting" definition as proposed in the Regulations described herein. Person-centered planning is what this is all about, and that should include a variety of residential options wherein the HCBS is available in all settings other than in ICF-MR's.

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In conclusion, President Obama, we urge you and your Staff to communicate with Secretary Kathleen Sebelius of HHS, and direct her to remove the offensive definition of "HCBS Settings" as described in proposed CMS -2296-P.

Sincerely,

Arlene Lakin, Esq.  
President  
Florida's Voice on Developmental Disabilities (FVDD)  
[www.Floridasvoice.org](http://www.Floridasvoice.org)

Copies of this letter are being mailed to the attached service list

SERVICE LIST

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- Donald Berwick, CMS, Washington, D.C.
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