

Commonwealth of Virginia



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November 5, 2013

The Honorable Kathleen Sebelius

Secretary, U.S. Department of Health and Human Services 200 Independence Avenue, SW

Washington, DC 20201 Dear Secretary Sebelius,

On October 31, 2013, the National Association of Councils on Developmental Disabilities (NACDD) sent a letter to CMS regarding the proposed rule 26379 for 1915(c) and 1915(i) that includes national standards for what constitutes a home and community-based (HCBS) setting for people with intellectual and developmental (ID/DD) disabilities. The Virginia Board for People with

Disabilities, Virginia’s Developmental Disabilities (DD) Council, supports NACDD’s position that “CMS regulations should ensure the rapid movement of individuals with developmental disabilities from institutions to community options with necessary supports and community programs.”

The Virginia Council has been actively engaged in policy discussions, workgroup activities and systems transformation initiatives associated with implementation of the Commonwealth’s Settlement Agreement with the Department of Justice. The Agreement is designed to ensure that individuals with intellectual and developmental disabilities (ID/DD) in Virginia are able to live integrated and full lives in the community while exercising lifestyle choices and decision-making authority.

Of concern to the Virginia DD Council have been recent attempts to develop gated segregated communities where individuals with ID/DD will reside. Such developments date back to an outdated “village” or “commune” service model that does not meet the principles of integrated, independent housing. While a number of examples exist around the country, one program now under development is Vanguard Landing in Virginia Beach, which plans to house up to 185

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individuals with intellectual disabilities within the confines of their gated community with the majority of activities, including work and day support, also being on-site (vanguardlanding.org). Vanguard Landing’s mission states it is *“To provide a safe, progressive, and self-sustaining community for adults with mild to moderate intellectual disabilities.”*

The Virginia DD Council recommends that CMS provide a clear definition of HCBS to mitigate the proliferation of these segregated and antiquated “communities” which more closely resemble an institutional model of supports. We recommend the following:

* The proposed rule 26379 (May 2013) notes that community based settings “do not include NFs…or other locations that have ***the qualities of an institutional setting*** as determined by the Secretary” “*the qualities of an institutional setting”* must be

delineated. As written, it is too vague. By contrast, the Money Follows the Person (MFP) program has clear definitions of what is considered community based on size (number of residents) and sets 25% as the proportion of apartment complex units which can be designated for people with disabilities in order to be considered integrated.

* “Other locations” should be defined, and the issue of integration vs. segregation must be clearly addressed. As written, the regulations appear to allow “neighborhood segregation,” i.e., a housing complex of multiple homes with bed capacity of 4 or less and an entire apartment building to be dedicated to those with ID/DD, which constitutes segregation.

To best serve individuals with developmental disabilities, HCBS standards should support access to the services, supports and accommodations needed to live and work in the setting that one has chosen and to participate fully in community life. The development of segregated “communities” is contrary to our beliefs and values, to the community integration mandate of the Americans with Disabilities Act, and to the Supreme Court Olmstead decision.

Thank you for consideration of these recommendations. Please contact me if you have any questions or need additional information. I can be reached by phone at (804) 786-9369 or by e-mail at Heidi.Lawyer@vbpd.virginia.gov.

Sincerely,

Heidi L. Lawyer

Cc: Ms. Marilyn Tavenner, Administrator, Centers for Medicare and Medicaid Services Ms. Cynthia Mann, Deputy Administrator, Centers for Medicare and Medicaid Services John Kelly, Chair, Virginia Board for People with Disabilities