

August 21, 2009

Centers for Medicare & Medicaid Services
Department of Health & Human Services
Attn: CMS-2296-ANPRM
P.O. Box 8016
Baltimore, MD 21244-1850

Re: Comments on CMS-2296-ANPRM

Dear Sirs/Madams:

I write on behalf of the Delaware State Council for Persons with Disabilities (SCPD) to provide comments on the CMS advance notice of proposed rulemaking (ANPRM) which announces the intention of CMS to publish proposed amendments to the regulations implementing Medicaid home and community-based services waivers under section 1915(c) of the Social Security Act and on the most effective means to define home and community.

As background, SCPD is charged in 29 Del.C. Section 8210 with the responsibility, in part, of proposing and promoting laws, regulations, programs and policies to improve the well-being of persons with disabilities. Consistent with its stated mandate, SCPD endorses providing States the option to combine or eliminate the existing three permitted waiver targeting groups. However, Council opposes the concept of linking services to housing. SCPD has the following observations on the intention to publish proposed amendments to the regulations.

1. Removal of the existing regulatory barrier regarding target groups will increase a State's ability to design service packages based on need, rather than diagnosis or condition, and strengthen person-centered principles. Moving from a silo-type system to a person-centered, functionally-based system will assist in breaking the culture that has developed over time that assumes that people with disabilities need programs to be pigeon-holed into, rather than allowing choice of support services based on functional need. This "program-pigeon-hole" culture helped create and expand costly, segregated nursing facilities, institutions, other congregate settings, and therefore allow discrimination against people with disabilities. In addition, in the current system, different eligibility criteria for different programs sometimes require people to move from one program into another program with different or even less support services simply because they become older. The proposed functionally based waiver would resolve this issue.

2. Allowing flexibility in waiver programs will enhance the State's ability to serve individuals requiring an institutional level of care and may better facilitate compliance with the Americans with Disabilities Act (ADA) and the Olmstead decision since states have difficulty adequately meeting the needs of people with disabilities in the current silo-funded waiver configuration.
3. Developing functional waivers as a choice for states will eliminate administrative duplication and waste. In addition, waivers based on functional need will make state waiver expenditures easier to track and therefore make the State budget process more predictable.
4. The ability to develop HCBS waivers on a functional basis may assist states in developing a uniform functional assessment, uniform contracting procedures, logical rate setting, uniform licensing, comprehensive quality standards, and uniform health and safety requirements. This functional system would also assist in logical long range planning based on actual need rather than the current one-size-does-not-fit-all disability label.
5. Cost neutrality should be based on a combination of aggregate expenditures, combining the numbers of persons in a functional waiver and comparing their costs to a combination of costs of people in the relevant institutions.
6. Housing services are critical to transitioning back to the community. The ANPRM notes that CMS is planning to amend the regulations to require persons in HCBS programs to reside:
 - in a home or apartment not owned, leased or controlled by a provider of any health-related treatment or support services; or
 - in a home or apartment that is owned, leased or controlled by a provider of one or more health-related treatment or support services, and that meets standards for community living, as defined by the State and approved by the Secretary.

SCPD believes that housing should be delinked from services if individuals are truly able to reside "where they can enjoy all the liberties of community living" and "be in a setting where they have maximum choice, control and individual liberties."

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on the regulations.

Sincerely,

Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

cc: Ms. Rosanne Mahaney
Developmental Disabilities Council
Governor's Advisory Council for Exceptional Citizens