

August 29, 2012

Sharon L. Summers
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RE: DMMA Proposed Programs of All-Inclusive Care for the Elderly (PACE) Regulation [16 DE Reg. 170 (August 1, 2012)]

Dear Ms. Summers:

In October, 2011, the Governor's Advisory Council for Exceptional Citizens (GACEC) and State Council for Persons with Disabilities (SCPD) endorsed a proposed regulation authorizing the establishment of a Program of All Inclusive Care for the Elderly (PACE) in Delaware. The regulation became final in December, 2011. See 15 DE Reg. 437 (October 1, 2011) (proposed); 15 DE Reg. 847 (December 1, 2011) (final). General background on this program is compiled in the CMS publication, "Quick Facts about Programs of All-inclusive Care for the Elderly (PACE)". In an October 17, 2011 presentation, the Delaware Health and Social Services (DHSS) Medicaid Director noted that the PACE program is intended to start on October 1, 2012. The Division of Medicaid & Medical Assistance (DMMA) envisioned partnering with St. Francis Hospital with a Wilmington service area. The DMMA website contains only a brief description of the program which was last updated on September 28, 2011. The DMMA is now proposing to adopt enrollment standards for PACE. Council would like to share the following observations on the proposed enrollment standards.

First, the key eligibility standards are compiled in §5. There is some "tension" between §5 and §9 in the context of nursing home residency. The CMS document indicates that seven percent of PACE enrollees live in nursing homes. Section 9 recites as follows:

9. Nursing facility services are part of the PACE benefit package.

The PACE Organization must notify the Division of Medicaid and Medical Assistance (DMMA) eligibility worker of the individual's placement in a nursing facility.

The PACE individual is not required to contribute to the cost of their care while in a nursing facility.

Thus, the CMS guidance and §9.0 suggest that residents of nursing homes may be eligible for the program. However, §5 requires, as a matter of eligibility for enrollment, that the applicant "(b)e

living in the community.” Council infers that an individual must be in the community upon initial enrollment but that “continued eligibility” is not affected by post-enrollment nursing home residency. It would be helpful if DMMA could clarify this aspect of eligibility.

Second, §10 b. contains the following justification for involuntary termination from the program:

Has decision making capacity and is consistently non-compliant with the individual plan of care and enrollment agreement, which may impact the participant’s health and welfare in the community;...

This section would literally authorize termination for recurrent “minor/inconsequential” non-compliance with “minor/inconsequential” impact on health and welfare. Providers have a financial incentive to terminate eligibility of “expensive” individuals and it would be preferable to deter involuntary termination in the absence of significant non-compliance. There is also no requirement that the non-compliance be “willful” rather than inadvertent. For example, an elderly individual’s plan may contemplate self-administration of medications. Due to memory deficits, the individual may periodically forget to take medications which affect the individual’s welfare. Under a literal reading of the regulatory standard, the individual could be terminated from the program based on consistent non-compliance impacting health. Consider the following substitute:

Has decision making capacity and is willfully and consistently non-compliant with material components of the individual’s plan of care and enrollment agreement which may significantly impact the participant’s health and welfare in the community;...

Third, §10.b. contains the following additional justification for involuntary termination from the program:

Engages in disruptive, threatening or non-compliant behavior which jeopardizes his or her safety or the safety of others;...

Individuals with Alzheimer’s, dementia, Tourette syndrome or Traumatic Brain Injury (TBI) may exhibit such behavior as a symptom of their disability. Terminating their eligibility for symptoms of disability would violate §504 and the ADA. CMS requires programs to provide accommodations to participants with disabilities, not get rid of them. See CMS Medicaid Director Guidance (July 29, 1998) and CMS Medicaid Director Guidance (May 10, 2010). See also October 11, 1985 HHS OCR LOF to Delaware DHSS which held the following regulation violated §504:

57.809 Mental Illness

A. Patients who are, or become, mentally ill and who may be harmful to themselves or others, shall not be admitted or retained in a nursing home.

OCR commented as follows:

Conditions such as Alzheimer’s Disease may be considered a mental impairment under the definition of handicapping condition; however the presence of this condition and its manifestations may in no way render one ineligible for the receipt of services normally provided. ...It is our preliminary determination, based on the preceding discussion, that Section 57.809 as written violates Section 504 of the Rehabilitation Act and its

implementing regulation 45 CFR Section 84.4 and Section 84.52(a)(1).

[emphasis supplied]

Rather than authorizing termination from the program, enrollees manifesting such behavior due to disability should be considered for specialized treatment. See, e.g., 16 DE Admin Code 3225, §§5.5, 5.12 and 7.0; and 16 DE Admin Code 3201, §5.6. Consider the following substitute:

Has decision making capacity and willfully engages in disruptive, threatening or non-compliant behavior which is not symptomatic of disability and which jeopardizes his or her safety or the safety of others;...

Fourth, it is unclear if “assisted living” services are part of the PACE benefit package. Compare §9.0. This could be clarified. Assisted living settings are required to be “homelike” (16 DE Reg. 3225, §3.0 (definition of “homelike”) and may be less restrictive settings than nursing facilities.

Fifth, the CMS document recites as follows: “If you disagree with the interdisciplinary team about your care plan, you have the right to file an appeal.” The DMMA regulation omits any reference to the right to a hearing to contest denial of program eligibility (§5.0); involuntary termination from the program (§10.0); and disagreements about the plan of care. It would be preferable to clarify that 16 DE Admin Code 5000 applies.

Thank you in advance for your time and consideration of our observations. Please feel free to contact me or Wendy Strauss should you have questions or concerns.

Sincerely,

Terri A. Hancharick
Chairperson

TAH:kpc

CC: The Honorable Rita Landgraf, Secretary of DHSS
Lucretia Young, AARP Delaware