

May 27, 2008

Centers for Medicare & Medicaid Services  
Dept of Health & Human Services  
Attention: CMS-2249-P  
P.O. Box 8016  
Baltimore, MD 21244-8016

To Whom it may Concern:

Reference: File Code CMS-2249-P

The Bazelon Center for Mental Health Law is submitting the following comments on the Proposed Rule for Home and Community-Based State Plan Services provided under the Medicaid program, as published in the Federal Register on April 4, 2008.

The Bazelon Center is a legal advocacy organization, based in Washington, D.C., concerned with the rights of children and adults with serious mental disorders.

1. Assessment Process (*Needs-Based Criteria and Evaluation*, 441-559)

The preamble makes it clear that inability to perform IADLs as well as other factors can be used to assess eligibility, and that while inability to perform two or more ADLs is a requirement of the assessment is not a prerequisite to receive home and community based services. This is a most important provision for persons with mental illness, whose functional impairments (by definition) relate to their mental capacities, not their physical abilities. However, the regulation does not specifically reference IADLs.

Recommendation: Paragraph 441.559(a)(2) should be amended to add a new paragraph that encourages states to include an assessment of the individual's need for support to perform IADLs, particularly for persons who have a mental impairment.

2. Independent Assessment (*Independent assessment*, 441.562 and 441.568)

We applaud CMS for emphasizing that individuals who make determinations of eligibility and assessments must be independent and free from conflicts-of-interest. We are concerned, however, with the exception to this rule in paragraph 441.568 that allows providers of services to perform these roles in certain circumstances. Providers in the public sector are always under significant fiscal pressure and also may not offer all the

services the person needs. There will be a tendency for any individual working for such a provider to limit the person's access to necessary services by finding them to be unnecessary. We therefore think this section should be strengthened. First, states should have to demonstrate to the Secretary that it is not feasible to hire independent evaluators/assessors in certain parts of the state (and CMS should clarify that it does not expect such a determination to find that no independent evaluators/assessors can be found anywhere in the state) before they can allow a provider to perform such duties. Secondly, we strongly support the provision in the current rule that provider agencies must have a firewall to separate the evaluators/assessors from individuals who provide direct services. Thirdly, individual consumers who are evaluated or assessed by provider employees should have a separate and easy process to appeal to the state if they are dissatisfied with the decisions being made on their behalf.

Recommendation: Paragraph 441.568(4) should be expanded to include the three criteria listed in the paragraph above.

3. Appropriate, Independent Living Situation (*Eligibility for home and community-based services under section 1915(i)(1) of the Act, 441.556*)

CMS has created provisions intended to ensure that individuals are placed in community settings that allow them the greatest possible independence. We strongly applaud the agency for this approach. Too often, persons with serious mental illness are moved from large and isolated institutions into smaller facilities, purportedly "in the community" that allow them little independence or personal freedom. We urge the agency to continue to include in the final regulation a description that aids states in understanding what is an acceptable community setting.

First, criteria that are listed in the preamble to the regulation could be very helpful to states if included in the regulation itself. Residences that meet certain standards, regardless of their size, could then be exempted from the requirement that the independent assessor make the determination. These standards would be: ability to control access to private personal quarters, with the option to furnish and decorate that area; the option to choose whether, and with whom, personal space is shared, unscheduled access to food and food preparation facilities, the right of the individual to choose activities in the community in which they wish to participate and the opportunity to come and go as they please. Also important would be freedom to consent, or not, to medical treatment and not to have their ability to remain in the residence dependent upon conforming to any specific medical treatment. None of these criteria are intended to suggest that residents who do not behave in an appropriate or considerate way have the right to remain regardless of their behavior. However, the standard should be their behavior and/or ability to live in safety, not their adherence to a specific treatment plan with which they do not agree.

Secondly, we agree with CMS that where a placement does not meet regulatory standards, the independent evaluator/assessor should determine, on an individualized

basis, whether this is an appropriate community placement for the person. Individual preferences as well as individual needs should govern this determination.

Recommendation: Paragraph 441.556(ii) should be amended to (1) delete the reference to the size of the proposed community residence, (2) to add criteria (including those listed now only in the preamble) for states to use to determine what is an appropriate community residence and (3) to add a standard that ensures that individuals have freedom to make their own decisions on treatment options by focusing on a person's behavior, not their adherence to a particular treatment regimen and (4) to retain the provision in the current rule regarding the need for the independent assessment to include documentation that the individual is living in a community setting and not an institution.

4. Income Eligibility Standards (*Eligibility for home and community based services under section 1915(i)(1) of the Act, 441.556*)

The regulation permits a state to use the more liberal income disregards used by the state for the eligibility group under section 1902(r)(2) of the statute. As a result, medically-needy individuals can receive home and community based services in the community by meeting income and resource standards for institutional care. For children with serious mental disorders, this provision can permit access to home and community based services and avoidance of institutional placement for some children whose families would otherwise not meet Medicaid financial eligibility standards. States have used a similar approach under Section 1915(c) waivers to provide otherwise inaccessible home and community based services to families who might otherwise be forced to relinquish custody of their children to the state or see their child go without essential service.

This is therefore an extremely important provision for children with serious mental disorders and their families, and we are pleased to see it clarified in the rule.

Thank you for the opportunity to comment.

Sincerely,

Chris Koyanagi  
Policy Director