

April 26, 2011

Centers for Medicare & Medicaid Services Department of Health and Human Services Attention: CMS-2337-P P.O. Box 8016 Baltimore, MD 21244-8016

## RE: Comments on CMS Proposed Rule for "Medicaid Program: Community First Choice Option" (42 CFR Part 441, CMS-2337-P, RIN 0938-AQ35)

## Submitted Via: http://www.regulations.gov

The undersigned disability organizations are members of the CCD Long Term Services and Supports Task Force and are submitting the following comments on the CMS Proposed Rule for the Community First Choice Option 42 CFR Part 441, CMS-2337-P, RIN 0938-AQ35. Individual organizations may submit additional, or more detailed, comments on specific issues.

CCD is a coalition of national disability organizations working together to advocate for national public policy that ensures the self determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society. Since 1973, the CCD has advocated on behalf of people of all ages with physical and mental disabilities and their families. CCD has worked to achieve federal legislation and regulations that assure that the 54 million children and adults with disabilities are fully integrated into the mainstream of society.

## **General Comments**

We commend CMS for underscoring throughout the proposed regulations the principles of consumer control articulated in the Community First Choice Option. Person-centered planning processes, choice in hiring, directing and firing workers, options for selfdirected service budgets, and establishment of a robust implementation council are all important elements that support participants as the central decision-maker in a longterm services and supports system.

## **Specific Issues**

**Sec. Background 1.A -** to the proposed rule delineates the important history of the CFC Option. While not critical to the implementation of the CFC Option, Section I.B. Background of Home and Community Based Attendant Services and Supports omits

discussion of the Section 1930 Community Supported Living Arrangements (CSLA) program which greatly influenced development of home and community based waiver services in the 1990's and which we believe is also an important cornerstone of the new program.

**Recommendation:** We believe the above statement should be in the final rule.

**Basis and Scope - §441.500**. We believe the scope should acknowledge that the Community First Choice Option is intended to make available to people with disabilities of all ages home and community-based attendant services and supports as an alternative to institutional placement.

**Definitions - §441.505**. We applaud CMS for prefacing the list of everyday activities with "including, but not limited to" to recognize that individuals may have additional needs for support.

**Recommendation:** The definition of "individual's representative" should explicitly include spouse and partner, and it should be clear that "authorized individual" is any person(s)—including paid and unpaid individuals—chosen by the Medicaid participant or family support who has been designated by the participant or family to represent the participant to the extent the participant wishes. The people chosen by the individual participant are to work in collaboration with the participant/family to reflect what is important to the individual to ensure delivery of services in a manner that reflects personal preferences and choices, including individual budgets, and personally-defined outcomes, preferred methods of achieving them, and the training supports, therapies, treatments, and other services the individual needs to achieve his/her outcomes.

**Eligibility - §510**. The Community Choice Act, upon which the Community First Choice Option is based, required all eligible individuals to have an institutional level of care need. CCD organizations that worked with Congress to achieve passage of Community First Choice Option are concerned that the statute and regulation which may be interpreted to extend program eligibility to lower income individuals who do not have an institutional level of care need, do not reflect Congressional intent. Some evidence of legislative history supports this conclusion. A summary of Senator Schumer's amendment adopted by the Senate Finance Committee and floor statements by Senator Harkin refer to an institutional level of care as the eligibility standard. However, the eligibility language as passed is unclear and no committee report was issued in the Senate.

Schumer Amendment #C13 to Title I, Subtitle G-Short Title: Community First Choice Option Description of Amendment:

Add the Community First Choice Option to the end of Title I, Subtitle G, Part IV (Medicaid services) or at the appropriate place within this Title.

The community First Choice Option would create a state plan option under Section 1915 of the Social Security Act to provide community based attendant supports and services to individuals with disabilities who are Medicaid eligible and who require an institutional level of care. These services and supports include assistance to individuals with disabilities in accomplishing activities of daily living and health related tasks. States who choose the Community First Choice Option would be eligible for enhanced federal matching funds for reimbursable expenses in the program.

The Community First Choice Option would require data collection to help determine how states are currently providing home and community based services, the cost of those services, and whether states are currently offering individuals with disabilities who otherwise qualify for institutional care under Medicaid the choice to instead receive home and community based services, as required by the U.S. Supreme Court in Olmstead v. L.C. (1999).

The provision would also modify the Money Follows the Person grant program to reduce the amount of time required for individuals to qualify for that program.

**Recommendation:** Based on the original intent of The Community Choice Act, we urge CMS to require that states that take up the CFC option must first address all individuals who have an institutional level of care need before a state opts to serve lower income persons who do not have an institutional level of care need. Furthermore, we recommend that states may establish medical eligibility criteria that would limit eligibility for the program to individuals who have an institutional level of care need, regardless of their income.

**Excluded Services - §525**. We commend CMS for proposing to only exclude coverage of assistive devices in circumstances where they would be the sole needed service in an individual's service plan. We concur that it is appropriate to pay for assistive technology, medical equipment, and home modifications when coverage is based on an identified need in an individual's service plan and used in conjunction with other home and community based attendant services.

**Recommendation:** We recommend CMS include in the final regulation that Medicaid reimbursement for room and board for a personal attendant is an allowable Medicaid expenditure. This recommendation is consistent with CMS (formerly HCFA) State Medicaid Director Letter from Mary Jean Duckett and included within the 1915(c) waiver guidance. CCD strongly believes the CFC regulation be consistent with current CMS policy and practice to states.

**Setting - §530**. We support CMS' continuing efforts to ensure that people receive supports in the most integrated setting appropriate to their needs and interpret some of the regulatory provisions in this section as being aimed at excluding settings for service delivery that are located on the grounds of an public or private institutions, including nursing homes, ICF/MRs, and hospitals. At the same time, we are concerned that CMS

might interpret or enforce language in this section (S.530 e) (disability specific housing) to exclude the delivery of attendant services in many settings that are the most integrated setting appropriate to individuals' needs. For example, for many years HCFA/CMS have encouraged HUD funding for Section 811 and 202 housing designated specifically for targeted populations with disabilities. Some of those HUD projects include individual apartments listed as "independent living" housing complexes for persons with specific disabilities.

**Recommendation:** We strongly recommend CMS to convene stakeholders to refine proposed policy on this issue.

**Assessment of Need - §535**. We believe that the proposed rule appropriately sets forth multiple factors that should be considered in determining the need for and authorization and provision of services. However, we question language in the preamble that suggests the assessment should include a determination of whether there are persons available to provide unpaid services. While we believe the existence of family and other informal supports could be considered, as appropriate, in determining the individual's needs, strengths and preferences, the existence of family and other informal supports should not be considered for the purpose of reducing either the scope or duration of services to the individual.

Program eligibility and supports covered for an individual by the program should be based upon functional need and not upon the availability of family or other informal caregivers. We would also suggest that in certain circumstances, it may not be necessary to conduct a face to face assessment of need every 12 months.

**Person-Centered Service Plan - §540**. We are pleased to see the proposed rules emphasize key elements that must be part of a service planning process in order to be considered "person-centered." We support establishment of protections for individuals from conflict of interest. However, we object to the proposed conflict of interest standards at (c)(4) that prohibit any involvement of family members and persons who are financially responsible for the individual with the service plan development process. These prohibitions may inappropriately undermine the preference of individuals to choose persons they wish to involve. The proposed prohibition undermines that preference. Finally we request clarification of what CMS envisioned when it included prevention of the "provision of unnecessary or inappropriate care" as one required criteria for a person-centered plan.

**Service Models - §545.** We encourage CMS to require a state to offer both an agency with choice delivery system model as well as a self-directed model with service budget.

**Support System - §555**. States should be encouraged to develop worker registries as part of the additional activities they undertake to support a self-directed model of service delivery.

**Provider Qualifications - §565**. We support the right of individuals to train workers in the specific areas of attendant care needed. CMS will need to clarify the interaction of

these rules with state laws that may specify mandated training requirements governing all attendant workers. We also believe that Community First Choice Option participants should have maximum flexibility to hire any individual capable of providing services and supports, including legally liable relatives.

**State Assurances - §570**. To the extent permitted under the law, we support limiting application of the state maintenance of effort requirement to a defined set of services rather than to all Medicaid expenditures for older people or persons with disabilities. However, we believe it should include all home and community based services, not just personal assistance services.

While states should have flexibility to move beneficiaries from other programs into Community First Choice Option, safeguards need to be in place to ensure beneficiaries do not experience any disruptions or loss of benefits and that they are able to retain their providers from the initial program if they previously directed their own supports.

**Development and Implementation Council - §575.** We are pleased that CMS is soliciting comments on ways to design the Implementation Council in a way that provides for robust stakeholder collaboration. We have several comments. First, states should be required to ensure that the Council's meetings and other functions are accessible and that supports are provided to individuals where needed to facilitate their full participation. Second, the statute states that the Council must include a majority of members with disabilities, elderly individuals, and their representatives. We believe the statutory language requiring a "majority" of members is more specific that the proposed regulatory language of "primarily" and urge CMS to use "majority" in the final rule. Third, the Council should be comprised of members that reflect the diverse populations covered by the Community First Choice Option and include individuals who are eligible to participate. Fourth, states should be directed to ensure that the Council coordinates with other state stakeholder bodies having related missions, such as Olmstead implementation councils and long-term services and supports commissions.

The availability of an adequate attendant services workforce is essential to ensuring that individuals' needs are met through Community First Choice Option. To expand and sustain the state's attendant services workforce we recommend that the Council be explicitly charged with developing a plan that insures the adequacy of provider rates and compensation; makes worker training available; establishes a central mechanism to help program participants find providers; and develops an approach to collecting essential workforce data elements. Direct service workers should be included among the Council's membership. In order to maintain quality assurance, we recommend states must continue to regularly consult with the Council and incorporate their recommendations into the operation of the Community First Choice Option.

**Data Collection - §580**. To assess the stability of the attendant service workforce and identify needed policy initiatives, we recommend that CMS urge states to collect data on worker availability, turnover and retention rates, and compensation. We recognize that in a self-directed delivery system, program participants will be the most likely source of

this data and urge identification of collection methods that will be feasible for participants.

**Quality Assurance System - §441.585**. It is very important that stakeholder feedback both through the Development and Implementation Council, consumer satisfaction surveys, and other means is included in the quality assurance system and language to this effect should be included in the proposed rule.

**Recommendation:** "(b) Stakeholder feedback. The State must elicit and incorporate feedback from key stakeholders, including the recommendations of the Development and Implementation Council and measures of consumer\_satisfaction, to improve the quality of the community-based attendant services and supports benefit."

The continuous quality assurance system must measure and report on achievement of individual outcomes and goals expressed by beneficiaries in their person-centered services and supports plans. Measurement and reporting should also include barriers to achievement of individual outcomes and goals and how the state intends to address and remove any identified barriers. The perspective of service recipients and advocates will be critically important in making determinations as to "quality," particularly as it pertains to personal goal and outcome achievement.

**Recommendation:** "(1) Program performance measures. The States' quality assurance system must be designed to measure and provide evidence of program performance related to the following: (i) Health and welfare, (ii) Provider qualifications, (iii) Choice of institution or community, and type of living situation such as group home, family home, individual's home or other. (iv) Choice of services supports and providers. (v) Cost of services and supports and (vi) Achievement of individual's outcomes and goals identified in the person-centered plan. (vii) Choice of location where the services are provided, such as home, school, work, or other. (viii) Consumer satisfaction.

(2) Quality of care measures. The State's quality assurance system must be designed to measure individual outcomes and goals indentified in the person-centered plan associated with the receipt of community-based attendant services and supports, particularly with respect to the health and welfare of recipients of this service. The State must identify barriers to achieving outcomes and goals of an individual's person-centered plan and provide a plan for addressing and removing said barriers. These measures must be made available to CMS upon request and must include a process for the mandatory reporting, investigation, and resolution of allegations of neglect, abuse, or exploitation in connection with the provision of community based attendant services and supports, as well as quality indicators approved or prescribed by the Secretary.

**Increased Federal Financial Participation - §590**. States should be permitted to receive the enhanced Federal Medical Assistance Percentage (FMAP) provided in the Community First Choice Option concurrently with receiving other HCBS enhanced match rates such as those authorized.

Thank you for the opportunity to provide these comments.

Respectfully submitted by:

American Association of People with Disabilities American Network of Community Options and Resources Association of University Centers on Disability Brain Injury Association of America **Easter Seals** Lutheran Services in America – Disability Network National Association for Community Behavioral Healthcare National Association of Councils on Developmental Disabilities National Association of County Behavioral Health and Developmental Disability Directors National Association of State Head Injury Administrators National Disability Rights Network National Multiple Sclerosis Society National Respite Coalition Paralyzed Veterans of America United Cerebral Palsy United Spinal Association