The Arc
For people with intellectual
and developmental disabilities

The Arc
1660 L Street NW, Suite 301
Washington, DC 20036

T 202 534-3700
F 202 534-3731
www.thearc.org

April 26, 2011

Donald M. Berwick, Administrator
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

Dear Administrator Berwick:

Thank you for this opportunity to comment on the Notice of Proposed Rulemaking (NPRM) for the Medicaid Program: Community First Choice Option, published in the Federal Register on February 25, 2011. These comments are submitted on behalf of The Arc of the United States.

The Arc has over 140,000 members and more than 700 state and local chapters made up of people with intellectual, developmental, and other disabilities, their families, friends, interested citizens, and professionals. The Arc has represented individuals with disabilities for 60 years.

The Arc and numerous other advocacy organizations have shared the goal of removing the institutional bias inherent in the Medicaid program for some time. We have worked for many years to achieve real choice in long term supports for individuals with disabilities. We worked on enactment of the Community First Choice Option and believe that the CFC Option is a positive initial step toward achieving our ultimate goal.

We commend CMS for infusing the principles of consumer control and person centered planning throughout the proposed rule. We support the premise that the CFC participant is the center of all planning, directs services, and is the decision maker about his or her long-term services. We also support the individual's choice to direct hiring, training, paying, and firing personnel.
Our comments pertaining to specific sections of the proposed rule follow.

Supplementary Information: I.B. Background of Home and Community-Based Attendant Services and Supports of 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.

Section 441.505 - Definitions. We applaud CMS for prefacing the list of activities under the definitions of activities of daily living and instrumental activities of daily living with "including, but not limited to" to recognize that individuals may have additional needs for support. (Under the IADL definition, the word "is" is extraneous in that phrase.)

The definition of "individual's representative" should explicitly include spouse and partner, and it should be clear that "authorized individual" is someone who has been designated by the participant or, where appropriate, the participant's family to represent the participant to the extent the participant wishes. It should be clear that this is a designation made by the individual and does not require a formal state process (such as guardianship).

Section 441.510 - Eligibility. This section would expand eligibility beyond the institutional level of care to include individuals with incomes below 150% of the federal poverty level who do not necessarily meet the institutional level of care. The legislative history and intent of the CFC Option clearly ties eligibility to the institutional level of care for all participants. The CFC option was based on the Community Choice Act which would end the institutional bias of Medicaid and provide real choice in long term services and supports. Level of care eligibility in the Community Choice Act, and the subsequent CFC Option, was intended to be institutional level of care for everyone. Income eligibility for the CFC Option was intended to be up to the state's allowed institutional limits (up to 300 percent of the maximum federal SSI benefit) with a requirement that states cover at least those with incomes up to 150 percent of the federal poverty level. CMS has combined these two requirements in an unintended manner.

Although we would welcome expansion of services to the broader population of individuals with disabilities, we are concerned about unintended consequences of opening the program to people who do not meet the institutional level of care with incomes at or below 150 percent of the federal poverty level. Expanding eligibility beyond institutional level of care could create a cost deterrent which states might not be able to overcome. The Arc suggests that CMS limit eligibility for the CFC option to what Congressional sponsors and advocates have always intended - institutional level of care. That eligibility criterion would be consistent with the original intent of CFC which was to establish an alternative to institutional placement for people who need that level of care.

During markup of what became the Affordable Care Act, the Senate Finance Committee considered and approved an amendment by Senator Charles Schumer (D-NY). The Senator's amendment led to inclusion of the Community First Choice Option in the ACA. The Finance Committee works with summaries and conceptual language through the markup stage; then,

Committee staff drafts actual legislative language prior to Senate floor action. The relevant portions of Senator Schumer's amendment considered during the Senate Finance Committee markup are as follows:

> 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 an 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 quality 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.
> …

We believe that legislative history and intent lends clarity to what is perhaps the inartfully drafted language of § 2401.

However, if CMS determines that it will persist in its interpretation of the statutory language to allow coverage of people who need less than an institutional level of care and who have income at less than 150 percent of the federal poverty level, we urge that CMS make it clear that states must serve people with an institutional level of need up to the institutional financial eligibility criteria, while serving people below institutional level of care as an optional add-on. States should not be allowed to choose to serve people with a non-institutional level of need while not serving those with institutional level of need.

Section 441.515 – Statewideness. We support the requirements in this section addressing the states' responsibilities for providing services on a statewide basis; in a manner that provides

services in the most integrated setting appropriate to the individual's needs; and in a manner that provides the supports that the individual requires in order to lead an independent life.

Section 441.520 – Required Services. We support the descriptions of required services. In (a)(1) regarding " hands-on assistance, supervision, or cueing", we urge CMS to consider whether the use of "and/or" would make it clearer that a combination of such methods may be used for any particular individual, depending on what is needed.

Section 441.525 - Excluded Services. 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.

Section 441.530 - Setting. This section would require CFC Option services to be provided in non-institutional settings. This is consistent with the program's purpose of providing an alternative to institutional care. We support the exclusion of institutional settings and settings on the grounds of or adjacent to institutions segregated from the larger community.

Section 441.535 - Assessment of Need. 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 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 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. At a minimum, if family members or other informal supports are identified in the assessment and/or plan, the CFC participant must indicate acceptance of the unpaid supports in lieu of provided services and the family members or other informal supports must indicate that they are willing and able to perform the tasks or roles identified for them. The recipient and the informal supporters must have the ability to no longer accept or to withdraw their support without harming the beneficiary – the beneficiary's service plan should be adjusted to reflect the lost support.

Section 441.540 - Person-centered service plan. 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, this section would prohibit a person related to the CFC Option participant by blood or marriage from being involved in the development of the person-centered service plan. While we understand the intent of this section, we believe that it could significantly compromise the ability of some people with intellectual disabilities to fully participate in the development of their plans. Frequently, it is a family member who is able to communicate the needs, wishes, and preferences of the individual with a significant intellectual disability. If that family member were

prohibited from participating in plan development, the individual's wishes would not be adequately communicated to others on the planning team. We recommend that this section be amended.

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.

Section 441.545 - Service Models. 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. We believe that the full intent of the statute cannot be fulfilled if states are allowed to choose an agency model alone.

Section 441.555 - Support System. 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.

Section 441.565 - Provider Qualifications. 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.

Section 441.570 - State Assurances. 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 the 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.

Section 441.575 - Development and Implementation Council. In response to the request for input concerning Development and Implementation Councils, The Arc suggests the addition of language that requires Council functions to be accessible and individual supports to be provided to ensure participation of all members.

We suggest that the term "representative" used in the section requiring a majority of members to be individuals who are elderly, have disabilities, or are the representatives of individuals with disabilities needs clarification. The Arc believes that the composition of the majority must include individuals with cognitive and other disabilities. To ensure that the perspective of individuals with cognitive disabilities is included, the majority must include representatives who have expertise and broad breadth of knowledge about the functional needs of individuals, such as those with intellectual disabilities and Alzheimer's disease, for example, and various models of service

delivery. Many individuals with cognitive disabilities require a chosen representative to enable their full participation. We believe the statutory language requiring a "majority" of members is more specific than the proposed regulatory language of "primarily" and urge CMS to use "majority" in the final rule.

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 states charge the Council with developing a plan that ensures 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.

Section 441.580 - Data Collection. 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.

Section 441.585 - Quality Assurance System. It is very important that individual and family feedback through the Development and Implementation Council, consumer satisfaction surveys, and other means is included in the quality assurance system. The quality assurance feedback loop and other mechanisms must take this information into account in considering improvements to the CFC Option program.

Section 441.590 - Increased Federal Financial Participation. States should be permitted to receive the enhanced Federal Medical Assistance Percentage provided in the Community First Choice Option concurrently with receiving other HCBS enhanced match rates such as those authorized by the Money Follows the Person Rebalancing Demonstration and the Balancing Incentive Payments Program.

Thank you for the opportunity to comment on these important proposed regulations to implement the Community First Choice Option.

Respectfully submitted,

Marty Ford
Director, Public Policy Office