



CAMPAIGN FOR Better Care

April 26, 2011

Dr. Don Berwick
Administrator
Centers for Medicare and Medicaid Services
Room 445-G Hubert Humphrey Building
200 Independence Ave. SW
Washington, DC. 20201

File Code: CMS-2337-P

Dear Dr. Berwick:

The undersigned members of the *Campaign for Better Care* appreciate the opportunity to comment on the CMS proposed rule on the Medicaid *Community First Choice Option*, published in the *Federal Register*, vol. 76, no. 38, pages 10735-10753.

The Campaign for Better Care is a broad-based coalition of consumer organizations with a direct stake in improving the health and quality of life for older adults with multiple health conditions and their family caregivers. We are committed to ensuring that new models of care delivery provide the *comprehensive, coordinated, quality, patient- and family-centered care* that individuals want and need.

The Campaign supports initiatives to expand access to Home and Community Based Services (HCBS). HCBS services perfectly match the intent of the Affordable Care Act (ACA) since they provide consumers with personalized support services *and* potentially save costs by reducing unnecessary institutionalization. Most importantly, they allow millions of older adults and people with disabilities to live independently, and at their maximum health and functional capacity.

The Community First Choice Option (CFCO) presents an important opportunity for states to expand access to HCBS services to populations within their Medicaid programs. The CBC applauds HHS for developing a regulation that emphasizes the need to maximize consumer self-direction of their own health care and leverage supports for consumers self-directing their care. Furthermore, the CBC appreciates that HHS has carefully thought about developing system-wide programmatic standards with respect to HCBS services and key related standards and definitions, such as “person-centered” services. We appreciate the challenges in setting out broader policy through the ACA § 2401 regulation, and commend HHS for the effort to lay the groundwork for the forthcoming ACA § 2402(a) regulation.

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The Campaign for Better Care is led by the National Partnership for Women & Families, Community Catalyst, The Leadership Conference on Civil and Human Rights, and the National Health Law Program – and funded by The Atlantic Philanthropies.

Nonetheless, the CBC provides comments to address some concerns in the proposed rule. In particular, we consider that some portions of the proposed rule do not include enough guidance. Without more details, states will lack the guidance to effectively implement CFCO options. More importantly, vulnerable consumers will lack the protections necessary to ensure that they have meaningful access to high-quality services. The CBC understands that HHS will be issuing additional guidance in conjunction with the development of this regulation; the CBC would like to encourage HHS to consider comments below for that guidance if they are not incorporated into the regulation. However, the CBC urges HHS to include the most important consumer protections within the proposed regulation – America’s vulnerable older adults and people with disabilities deserve to see their well-being safeguarded in formal regulation.

§441.505 – Definitions

We commend the use of broad definitions, such as those for Activities of Daily Living and Instrumental Activities of Daily Living including the language “but not limited to”, which will allow flexibility to consider the supports needed by a wide range of individuals with functional limitations.

We commend the inclusion of examples, but recommend that additional examples of the term “Backup systems and supports” be included, such as medication management and tele-health care technologies.

We recommend that the term “Individual’s representative” be defined to also include “spouse” and “partner”.

§441.510 – Eligibility

The CBC commends the regulatory decision to allow states to cover populations up to 150% of the Federal Poverty Level (FPL) without a required showing of nursing facility clinical eligibility (NFCE). The population below 150% of FPL is extremely vulnerable, with the poorest health status and the least personal resources to acquire additional services and supports. States which choose to cover this population at levels of acuity below NFCE will help lessen any potential functional decline to NFCE status for these vulnerable individuals in the state.

The preamble to the proposed rule suggests, but §441.510 does not mention, the requirement for a yearly verification of income for CFCO applicants since this may be relevant to the level of care requirement for eligibility. We recommend that this requirement not be included, since income verification requirements are already a standard part of the Medicaid redetermination process. There is no need to create an additional and redundant barrier to eligibility. Furthermore, states should be encouraged and reminded of any authority to use ‘passive redetermination’ methods, which result in far fewer accidental and unwarranted terminations, and less administrative burdens for individuals and state programs alike.

§441.520 – Required Services

The CBC notes that the inclusion of “permissible” services within the “required services” subheading may create confusion in program administration, and the two sections should be separated for clarity.

We understand that in §441.525 you have included language allowing some exceptional services “based on a specific need identified in the service plan”. While we understand the need for that language in reference to exceptional excluded services, we believe the inclusion of this same language at §441.520(b)(3) may be overbroad when applied to all permissible services, and consider that this language could put a difficult burden on consumers to identify all possible future support needs during the care assessment phase.

§441.525 – Excluded Services

We commend the expansion of coverable services to include:

- Some services that may fall under “§441.520(a)(5)”; and
- Some that may be “based on a specific need identified in the service plan when used in conjunction with other” HCBS services.

With regard to the former, we note the technical error in the regulation referring to “§441.520(a)(5)” (there is no (a)(5) provision), and suggest you replace that reference with §441.520(a). With respect to the latter, we have understood your inclusion of this language to limit the circumstances when assistive technology could be covered (i.e., as an exception to the general policy of non-coverage). We strongly support this exception and note that it is cost-effective to substitute technology for attendant staff. However, we believe the inclusion of this same language at §441.520(b)(3) may be overbroad when applied to all permissible services, and consider that this language could put a difficult burden on consumers to identify all possible future support needs during the care assessment phase.

We commend your inclusion of the language “that are related to education only” in (b).

We note your request for comment on a proposal to allow states to determine at what point the amount of funds to purchase devices and adaptations places them in the statutorily excluded categories. This language appears in the preamble, but not the regulation. We are concerned that regulatory language on this point might confuse the *cost* of service with the *type* (or purpose) of service. State should not have absolute discretion to target exclusions strictly based on cost.

You state in the preamble that CFCO “would not include services furnished through another benefit or section under the Act.” We consider this statement to be overbroad and recommend it be altered to avoid confusion. We suggest editing it to read that CFCO “would not include certain specific types of services furnished through another benefit or section under the Act.”

§441.530 – Setting

We commend HHS's principled effort to develop consistency in defining HCBS settings across Medicaid programs. We realize that it is extremely difficult to develop criteria for settings that can precisely describe the fine line between institutional and community based settings. We recognize further that one set of criteria, when applied to the wide range of functional needs among older adults and people with disabilities, often leads to problematic results. We encourage you to ensure that your rule is inclusive of two critical needs. First, the need for some populations to reside in settings that are similar to assisted living, so that they can maximize their independent living while at the same time accessing support services to keep them healthy and safe. Second, the need for some people with disabilities with very particular functional limitations to receive support services in more structured environments.

§441.535 – Assessment of need

We commend the effort to identify key elements of assessment to be applied across programs, as discussed in the preamble. We also commend the specific inclusion of criteria in subpart (a), and the range of triggers and periodicity for reassessments in subpart (e). With regard to the requirement for face-to-face assessments, we would recommend a slight modification of the policy to include the right to a face-to-face interview (we commend your inclusion of this policy), along with authority to waive that requirement when the consumer or their identified representative affirmatively waive the right because they consider that it would be burdensome for them to comply based on their functional limitations.

Our greatest concern with this subsection is the inclusion of language in the preamble stating that the assessment should include "a determination of whether there are any persons available to support the individual, including family members." Family and other informal caregivers provide valuable support for many individuals and should be integrally involved in the assessment process. However, not all informal caregivers are equipped or trained to meet the often significant needs of their family members, and many struggle with significant health problems and/or functional limitations of their own.

Therefore, an assessment of need must measure a person's actual need for functional supports and not consider the availability of informal caregivers.

We are also concerned that the proposed policy would create harmful incentives on family and support structures, for example, putting an older adult in the position of choosing between remaining in a home with a relative or maintaining a lone address to qualify for support services.

The statutory language describing assessment of need includes a requirement that the assessment be "agreed to in writing" (see Social Security Act §1915(k)(1)(A)(i)). The proposed regulation should explicitly include this language in §441.535.

We consider subpart (a) to require clarification. It is unclear if the term "may" makes the entire subpart optional. Furthermore, the list of items does not clearly correspond to "processes and techniques" (they seem closer to "criteria"). Additionally, on the basis of using as few as one such process or technique, the assessment could in theory be based on a very limited information set (for example, only "school").

Most importantly, it is unclear what the extent of these processes and techniques are, and what role the consumer has in selecting (or prohibiting) the use of specific processes and techniques. We recommend:

- “Processes and techniques” should be changed to “criteria”.
- Certain criteria should be mandatory – such as health condition, personal goals and preferences, functional limitations, age, and “other factors”.
- “Health condition” should be expanded to read “Health condition and treatments”.
- The other criteria should be optional – but in all cases should not exceed the scope of the consumer interview conversation (i.e., collateral contacts should not be allowed unless requested by the consumer).
- “Household” may be relevant to understanding the consumer’s functional limitation, but should not be a basis for lowering a needs determination based on availability of other people. “Household” in this context should be edited to read, “Household and physical living arrangements, including the safety of those arrangements”.

We do not understand the purpose of subpart (b) in the context of a section on assessment of need. Subpart (b) seems to address when a service plan and/or budget can be developed. We recommend this subpart be clarified or deleted.

We note that §441.535(c) uses the word “or” to link the various clauses, whereas §441.540(e) uses the word “and”. We believe the regulatory intent was to have a uniform policy. We would like the policy to ultimately guarantee that a service plan would always be reviewed “at the request” of the consumer, and this meaning is best implemented by using the word “and”. We further recommend that timeframes be provided for conducting these reassessments, including a standard timeframe and an emergency timeframe to address situations where the consumer’s health or safety may be in jeopardy.

We note that as a practical matter that many states will be integrating their new CFCO assessment processes with existing HCBS assessment processes. We are concerned that states will poorly integrate the new CFCO assessment requirements, leading to failure to actually obey all of the regulatory mandates. We suggest that states be required to have a publicly available written plan explaining how the CFCO assessment process will work, interact with existing process, and ensure the regulatory requirements are met.

We recommend that the regulations require assessments to be conducted in a linguistically and culturally appropriate manner for the needs of the individual (and/or their appointed representative), as determined by the individual, and in a fully accessible way including supports for all functional limitations.

§441.540 – Person-centered service plan

The CBC believes that person-centered service plans are a critical element in the CFCO option as they result in consumer health care participation, greater independence, and better health outcomes. We commend the effort in the regulation and preamble to the regulation to develop core standards of person-centered planning, in terms of both process and plan.

We recommend that subpart (a)(7) be expanded to read: “Includes a method for the individual to request updates to the plan, and a timeframe for completing this update”.

We recommend that subpart (b)(8) be expanded to read: “Include a timeline for review and implementation of changes”.

We recognize that there may be rare instances that raise concerns about conflicts of interest around the creation of service plans, and understand your inclusion of a conflict of interest provision at §441.540(c). In our experience, however, the primary conflict of interest problem in the care planning process involves the pressure on state agencies and their contractors to keep spending at specified levels, promote/discourage the use of certain services based on cost and availability, or enforce unwritten rules about typical levels of services. Individuals are regularly steered away from services they may need on the basis of these pressures, as opposed to their assessable functional needs. We recommend that the conflict of interest provision, if necessary, should also address these conflicts which limit consumer access to services they need.

We further recommend that in subpart §441.540(c)(4) the language “involved in” be changed to “conducting”. The conflict of interest provision should apply only to the team conducting the assessment and creating the plan, and should not proscribe individuals participating in the process as a support to the consumer applicant. For example, a relative may be “involved in” the process to help the consumers with any one of a number of functional limitations, assist with communication, or distribute and collect materials.

The regulation at subpart (d) requires that the plan must be agreed to in writing by the individual. We understand it is HHS’s intent (as explained in the preamble) for the entire plan to be in writing, but believe the regulation only requires “signing off” on the plan in writing. We think a written record of consumer approval of the plan is an important component, but believe this statement to be too limited. We recommend specific requirements to put the plan itself in writing, for the consumer to have adequate time to review the plan themselves or with others, and of course the requirement for the plan to be agreed to in writing.

We recommend that the following sentence be added to the end of the language at subpart (e): “The review and revision of the service plan must be conducted according to an established timeframe that is explained to the consumer.”

We recommend that the regulations require the development of the service plan (including a copy of the service plan to be provided) in a linguistically and culturally appropriate manner based on the needs of the individual, as determined by the individual, and in a fully accessible way including supports and formats for all functional limitations.

§441.545 – Service Models

We commend the allowance for multiple service models. The CFCO population will include individuals with a diverse range of function limitations and supports needs and thus we appreciate your effort to create multiple service models to meet this diversity. We would specifically like to commend your

inclusion of language at subpart (a)(2) regarding the hiring and firing of providers. We would also like to commend your efforts to think about coordination of these model structures with other HCBS programs, such as 1915(j).

In the opening language of this subpart, in reference to the service models broadly, we recommend your specific inclusion of the statutory language regarding maximized consumer control found at 1915(k)(1)(A)(iv)(II) in the statute. We understand that this has been incorporated by definition into the term “self directed”, but consider it important here for clarity.

We commend your addition of important provisions regarding self-directed models. Specifically, we applaud the inclusion of specific functions the financial management agency should perform. We also commend the helpful details for the direct cash model you have included at subpart (b)(2)(ii) to (b)(2)(iv).

§441.550 – Service plan requirements

We believe this section includes some important elements for the development of self-directed models of care. Specifically, we commend and support the authority conveyed to consumers to: recruit and hire workers in subpart (a), fire workers in subpart (b), supervise workers in subpart (c), manage workers in subpart (d), and review and approve invoices in subpart (f). We consider that these five subparts are essential to meaningful self-directed models of care and encourage their inclusion in the final regulation.

§441.555 – Support System

We commend the inclusion of this subsection, and strongly endorse it as a critical component to ensuring that consumers achieve maximum independence. We commend the inclusion of a detailed set of supports requirements, including key requirements such as language access supports and counseling on options, service changes, grievances and individual rights. We recommend that subpart (b)(1) be extended to require communication in a culturally appropriate manner and with accommodations for all functional limitations, including the need for alternate formats.

We note that the regulation applies these supports to the self-directed model population, but that some of these supports may also be relevant and important to individuals in the agency. We recommend you consider extending the relevant support requirements to that population as well.

§441.560 – Service budget requirements

We commend the inclusion of this subpart and the requirement for states to develop clearer standards around setting budget limits, and how individuals are notified, empowered and safeguarded around budgets and adjustments. We also specifically commend the requirement that budgets not restrict access to other medically necessary care at subpart (e).

§441.565 – Provider qualifications

We commend the inclusion of protections such as the requirement to define qualifications in writing in subpart (a), the right to train workers per consumer preferences in subpart (c), and the right to establish additional qualifications based on need in subpart (d).

We note (and have commended) that the regulation requires the state to have safeguards and defined qualifications in place, but the regulation does not actually state the statutory requirement that services be provided by an individual who is qualified. We recommend stating this explicitly. At the same time, we note that sometimes provider qualification requirements can threaten the ability of consumers to actually staff their support needs, either because they present an administrative burden in the hiring process, because of market labor shortages, or because the consumer has highly specialized needs that don't fit into the standard market model. We therefore make two further recommendations:

- First, there should be an exceptions process if there is no satisfactory worker available and the consumer makes a voluntary affirmative choice to waive the provider qualifications requirement. We urge you to define “voluntary affirmative choice” in a way that will allow informed and sophisticated consumers to have the default requirement for provider qualifications waived, but that will at the same time not allow this authority to be abused. For example, an agency should not be able to offer an unsuspecting consumer a waiver to ‘get a faster attendant placement’.
- Second, the administrative burdens of ascertaining and evaluating provider qualifications should not fall so heavily on consumers so as to prevent hiring.

We recommend that in subpart (b) the term “family members” be broadly defined to include legally liable relatives and others who play a similar role supporting the consumer.

§441.570 – State assurances

Although the preamble (on page 10744) states that the Maintenance of Effort (MOE) requirement will be limited to spending on personal care services, this requirement does not appear in regulation. This is a significant decision which should be clearly stated in the regulation – although we disagree with the standard you have selected.

We understand and agree with the need to develop a standard which more accurately reflects the legislative intent to develop an MOE requirement for the CFCO. We agree that, for example, an MOE applying to *all* services for older adults and people with disabilities would be overly broad and render the MOE provision nearly pointless. However, we consider that limiting the application only to personal care services is overly narrow, and will not reflect the true scope of the CFCO program. We recommend, therefore, that the MOE be applied to all home and community based services for older adults and people with disabilities. We think that standard would match the legislative intent and be a reliable gauge of state compliance with the spirit of the MOE provision.

We expect that some states who take the CFCO will shift services for some consumers from other channels to the CFCO. We recommend a requirement that these shifts in services be conducted in a way

that does not negatively impact continuity of care. The administrative shift to CFCO financing should be seamless for consumer support services.

Furthermore, we believe that the legislative intent of the MOE provision was to ensure that states implemented the CFCO to expand access to services, and not as a way to constrict existing services (while securing higher matching funds). We believe there should be extra scrutiny of state reductions in services that are related to taking the CFCO option, and in particular, where the state makes no effort to grandfather in existing services for affected consumers. For example, if a state were to take the CFCO option and apply an NFCE medical necessity standard, it might be tempted to eliminate its personal care option to get higher match for those services through CFCO. However, the large majority of states do not have an NFCE level of need requirement for the personal care option – and thus many individuals who were in the personal care option would not be able to transition to CFCO. The state would likely not be in technical violation of the MOE, based on the broader CFCO spending obligations, but it might violate the spirit of the CFCO for thousands of consumers to find themselves without personal care services. HHS should be careful to avoid helping states evade the purpose of the MOE requirement.

§441.575 – Development & Implementation Council

We consider consumer participation in the development and implementation of CFCO programs to be vitally important. This section of the regulation merely restates the basic statutory requirement, and we recommend that significant content be added here. We understand that you may have concerns about how the Council interacts with existing state stakeholder processes. While we appreciate the need to coordinate with existing state structures, we also believe that it is vitally important to establish some baseline definitions and minimum participation standards. We do not think this is inconsistent with your objective to coordinate with existing state structures when they are acceptable. We think the regulation must at a minimum address the following:

- **Consumer Representatives.** The regulation must explain who, absent the ability of a consumer to participate directly, can appropriately be considered the representative of a consumer. We note that ambiguity in the term “consumer representative” could lead to it being interpreted as an individual representing an individual consumer or an employee of an advocacy organization representing consumers more broadly, or both. While we consider representatives from advocacy organization to be important, we believe that there may be many groups who self-identify as consumer advocacy groups but in fact are not in any way guided by or accountable to real consumers. We recommend that representatives from advocacy organizations should be limited to organizations that are connected to consumers, and that they should participate on the Council, but they should never hold the majority of dedicated “consumer” positions. The objective should be to draw the standard narrowly enough to ensure that designated consumers truly speak for consumers, but to leave some flexibility if it is difficult to find consumers who are able to participate.
- **Older adults and people with disabilities.** The regulation should define who can be considered an aging or disability consumer. For example, could an older adult who is not Medicaid eligible or not low income, hold a position on the Council? We recommend that “consumer” slots on the Council be reserved for actual Medicaid enrollees, potential CFCO

beneficiaries, or some other measure reasonably related to the population the council will be advocating for.

- **Balance between and within aging and disability.** We recommend that the regulation do two things. First, it should require a fair balance between aging and disability consumers. Second, it should require that the participating aging and disability consumers represent the full spectrum of functional need for the populations. For example, a Council should not be permitted to include only older adults who have a low acuity level, or include people with disabilities who have similar types of disability (such as three individuals who have a physical disability but none with an intellectual disability).
- **Consumer resources.** Meaningful participation on the Council necessitates that consumers have available resources to support their participation, in accessible languages and formats. The Council is likely to require understanding complex topics or accessing public documents, and consumers will need support to fully participate. We recommend that support resources be required to be available. For example, consumers should be allowed to have local legal services advocates accompany them to meetings as they do in many Medical Care Advisory Committee structures (as an example, see the Pennsylvania MAAC structure). We further recommend that the regulation require that meetings and key documents be fully accessible to older adults and people with disabilities, with participation accommodations made as necessary (for example, a consumer with a disability should be allowed to call-in to in person meetings, if they choose to).

We encourage the inclusion of provisions to require diversity among the non-consumer slots on the Development and Implementation Council, including key stakeholders such as aging and disability advocacy organizations and direct care workforce representatives.

The statute requires that there must be a “majority” of consumers, but the regulation instead uses the term “primarily” of consumers. The term majority has a clearer meaning, and we therefore recommend that the regulation use “majority” instead of “primarily”.

§441.580 – Data Collection

We commend the inclusion of subpart (c), collecting information about individuals serviced under state CFCO programs. This data will be an essential tool to identify deficiencies in the provision of the benefit, and to target remedial responses and reduce health care disparities. With respect to subpart (c) we make three recommendations. First, we recommend that the regulation require recording the number of individuals served both in terms of the number of individuals eligible to receive CFCO, and in terms of the individuals receiving all of the various CFCO services. Second, we recommend that data collection include tracking about the number of shifts that went unstaffed, as well as general availability, turnover and retention of attendant staffing. Third, we recommend that the break-down of data include additional fields, namely: race, ethnicity, limited English proficiency, and type of residence.

Subpart (e) should be edited for clarity. We understand the word “how” to refer to what delivery models the state uses and with what frequency each is used. We commend the required collection of this valuable data point.

We look forward to working with HHS on the development of future guidance on data collection reference in the preamble.

§441.585 – Quality Assurance

We commend the inclusion of the examples of measures of function indicators and individual satisfaction in the preamble. However, we recommend that a set of minimum measures should be included in the regulation. This will both ensure states are collecting core meaningful quality measures, and also allow for comparison of different programs to help identify best practices. We recommend the required collection of a core set of function indicators which are representative of the full range of functional limitations for the CFCO population, as well as measures of both patient satisfaction and patient experience.

We also recommend that the quality assurance system address the topics we identified above in §441.580 “Data collection”, namely:

- Numbers of individuals served both in terms of the number of individuals eligible to receive CFCO, and in terms of the individuals receiving all of the various CFCO services;
- Numbers of shifts that went unstaffed, as well as general availability, turnover and retention of attendant staffing; and
- Access to services on the basis of fields identified in §441.580(c), and additionally race, ethnicity, limited English proficiency, and type of residence.

We recommend that as part of their quality assurance system states be required evaluate whether the payment methodologies for attendant services and supports that are sufficient for developing and sustaining an adequate workforce, and the impact direct care workforce wages have on the access consumers have to a wide range of reliable, timely home and community based services.

We commend the specific requirement that the quality assurance system be detailed in the State plan amendment.

We note that at subpart (a)(2) the regulation applies the statutory requirement regarding reporting and investigation of abuse and neglect. While we commend the connection of abuse and neglect reporting to quality of care measures, we believe that the statute (at §1915(k)(3)(D)(iii)) applies the requirement more broadly than to the more limited subpart of “Quality of care measures” located at (a)(2). This is a vital requirement for ensuring consumer safety, and while it should be included or referenced in the quality of care measures section, we recommend that it be more broadly set forth as an independent requirement under the quality of assurance system (for example, under a new subpart (d) entitled “Process for Allegations of Abuse and Neglect”).

We recommend that at subpart (b) the language of the statute (at §1915(k)(3)(D)(ii)) should be used instead of the term “key stakeholders”.

Thank you again for the opportunity to provide comments.

Sincerely,

Advocacy for Patients with Chronic Illness, Inc.
Alzheimer's Association
American Hospice Foundation
Center for Medicare Advocacy, Inc.
Community Catalyst
Community Legal Services, Inc., Philadelphia
Consumer Health Coalition
Consumers for Affordable Health Care
Family Caregiver Alliance
Health Care for All
Medicare Rights Center
Medically Induced Trauma Support Services (MITSS)
National Alliance for Caregiving
National Coalition of Consumer Organizations on Aging (NCCO)
National Health Law Program
National Partnership for Women & Families
North Carolina Justice Center
Oregon State Council for Retired Citizens
OWL - The Voice of Midlife and Older Women
The Empowered Patient Coalition
The Leadership Conference on Civil and Human Rights
National Coalition of Consumer Organizations on Aging (NCCO)
UHCAN Ohio
United Seniors of Oregon
Well Spouse Association