



For people with intellectual
and developmental disabilities

The Arc
1825 K Street NW, Suite 1200
Washington, DC 20006

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

March 16, 2012

Ms. Melanie Bella, Director
Medicare-Medicaid Coordination Office
Centers for Medicare and Medicaid Services
7500 Security Boulevard
Baltimore, MD 21244

Submitted via MedicareMedicaidCoordination@cms.hhs.gov

Dear Ms. Bella:

The Arc is a membership organization of over 700 state and local chapters made up of people with intellectual, developmental and other disabilities, their families, friends, interested citizens and professionals in the disability field. The Arc has represented individuals with the most significant disabilities for over 60 years. The Arc submits the following comments concerning the Massachusetts Demonstration Proposal to Integrate Care for Dual Eligibles.

C. Care Model Overview

i. Proposed delivery system model

a. integrated care organizations (ICO)

The proposal calls for person-centered care and person-centered medical homes but does not address what “person-centered” actually means nor what person-centered planningⁱ really entails. Greater emphasis should be placed on person-centered planning (PCP) which must be the centerpiece of integrated care. The proposed plan should:

- Require ICOs and care teams to use PCP.
- Require ICOs to demonstrate literacy about the fundamentals of PCP.
- Require ICOs to include training of providers in PCP.
- Require ICOs and care teams to use independent PCP facilitators.
- Include PCP and delivery of services outlined in a person-centered plan as part of state-level and ICO-level monitoring systems.

b. Primary Care and the Care Team

Care Coordination and the Role of the Care Team

Care coordinators should be independent of the ICOs to ensure that the goal of achieving cost efficiencies does not trump the goal of improving client outcomes. The proposal should detail

Achieve with us.

how independence of care coordinators will be guaranteed since the ICOs will be the funding source for care coordinators. Including independent LTSS coordinators who will be provided through contracts with community-based organizations in the model is a very positive feature.

d. Provider networks

In addition to requiring ICOs to have sufficient providers to deliver all covered services, they should be required to have sufficient providers to ensure consumer choice. In part that requirement is operationalized by requiring ICOs to outreach to providers with existing relationships with enrollees and to continually enroll interested providers; however, the need to provide consumer choice should be an affirmative requirement.

e. Enrollment method

An “opt in” enrollment process would reflect true consumer choice and would be preferable.

It appears that all eligible people will be invited to enroll in ICOs beginning in October 2012 and that ICOs will enroll all members starting in January 2013. Advocates sought a phased-in enrollment. It is not entirely clear how enrollment will occur – if all members will enroll in January and potentially overwhelm the system causing unnecessary confusion and delays or if some phased-in approach is contemplated.

The impartial enrollment broker should be required to demonstrate capacity to accommodate a wide range of disabilities, including providing individualized assistance to enable informed decision making.

ii. Benefit design

Since ICOs will determine prior approval requirements and have approved procedures for determining necessary services, the definition of “medical necessity” will be critically important. Some people with disabilities require community-based long term services and supports that may not be the types of services ICOs typically view as “medical.” The definition should be based on extensive involvement of persons with disabilities, their representatives, and their supporters to ensure that services needed to promote community living are not denied because they do not meet a narrow view of medical necessity. The term “medical necessity” must refer to what is medically necessary for a particular individual, and entails an individual assessment rather than a general determination of what works in the ordinary case. The state should adopt a sufficiently expansive definition of medical necessity that all ICOs must use. This definition should include all LTSS available through Medicare and Medicaid for people who need them.

Enrollees will have access to internal and external grievance procedures. The proposal should delineate what safeguards will be in place to protect people from harm during disputes. The state also should develop a mechanism for people to directly contact the state that is in addition to the formal grievance processes.

a. Joint Medicare and Medicaid Services

ICOs should be required to provide self-direction as an option to all enrollees who want to self-direct services and control their own budgets and not just to enrollees using personal care assistance services. The Commonwealth will need to ensure that ICOs and providers have extensive training in self-directed services.

b. Additional Coordinated Behavioral Health Services

Additional behavioral health diversionary services are a positive expansion for people. However, ICOs will need to understand that the nature of those services may vary significantly depending on the nature of the enrollee's disability. The skills necessary for providing mobile crisis intervention services to individuals with developmental disabilities are a unique subset of behavioral health services. Given appropriate interventions, providers can divert individuals from costly and inappropriate emergency rooms, psychiatric hospitals, and jails.

d. Adjusted care model for specific services and populations

The rationale given for continuing to provide HCBS services to enrollees through waivers is worth highlighting.

Offering the full range of HCBS waiver services for all Demonstration enrollees, regardless of level of care need, is neither necessary nor affordable. As this is a new model of care and a significant expansion of managed LTSS for Massachusetts, it will be important to take time to build capacity and a strong infrastructure for the full gamut of intensive waiver services. As with TCM and the Rehabilitation option, population-based state agencies have long-standing relationships with HCBS waiver participants, and have long coordinated those individuals' State Plan and waiver LTSS. For those enrolled in a HCBS waiver, there is concern that, within the three-year period of the Demonstration, ICOs would not be able to replicate the extensive and fundamental LTSS needed by these specific populations, or to add sufficient value by changes to service arrangements for these members.

The Commonwealth's plan to establish mechanisms to coordinate health care and LTSS for people currently receiving services through HCBS waivers is a reasonable approach and focuses attention on the portion of services where improved outcomes for people and cost efficiencies are actually feasible during the demonstration period. Since Massachusetts has so few people receiving institutional care in ICFs/ID, and since those services will not be included in the proposal, the prospect of finding cost savings in the provision of LTSS through ICOs is remote. CMS should approve the Commonwealth's request to create a different benefit "tier" for people enrolled in HCBS waivers.

D. Stakeholder Engagement and Beneficiary Protections

ii. Beneficiary protections

a. Americans with Disabilities Act (ADA)

In addition to physical and communication access, the proposal should stress the importance of programmatic access (making health self-management, counseling, and wellness programs accessible to people with intellectual disabilities, for example). There should also be a strong

emphasis on providing services in the most integrated setting appropriate. This will be especially important as ICOs ensure provision of LTSS needed by people not receiving waiver services in order to participate fully in their communities.

F. Expected Outcomes

i. Key metrics related to the Demonstration's quality and cost outcomes

The dearth of measures to assess the quality of LTSS is of great concern and reinforces our belief that including LTSS for people with developmental disabilities in integrated coordinated demonstrations is premature. Until valid reliable quality measures are adopted, states should not turn over responsibility for those services to ICOs.

ii. Potential improvement targets

Part of the Commonwealth's quality monitoring system should include data by disability type about unmet needs, delays in service, and utilization of services. Independent entities should obtain consumer satisfaction and dissatisfaction input. The entities should include enrollees and their representatives.

Thank you for this opportunity to comment on the Massachusetts proposal. If you have any questions, I would be happy to provide further information.

Sincerely,
Maureen Fitzgerald
Director, Disability Rights

ⁱ The CMS definition of person centered planning used in the proposed rule for the Community First Choice Option program is a good starting point. There are myriad resources available to states about how to facilitate true person centered planning.

The person-centered approach is a process, directed by the individual with long-term support needs, or by another person important in the life of the individual who the individual has freely chosen to direct this process, intended to identify the strengths, capacities, preferences, needs, and desired outcomes of the individual. The person- entered process includes the opportunity for the individual to choose others to serve as important contributors to the planning process. These participants in the person centered planning process enable and assist the individual to identify and access a personalized mix of paid and non-paid services. This process and the resulting service plan will assist the individual in achieving personally defined outcomes in the most integrated community setting in a manner that reflects what is both important for the individual to meet identified support needs and what is important to the individual to ensure delivery of services in a manner that reflects personal preferences and choices and assures health and welfare. The individual identifies planning goals to achieve these personal outcomes in collaboration with those that the individual has identified. The identified personally-defined outcomes, preferred methods for achieving them and the training supports, therapies, treatments, and other services the individual needs to achieve those outcomes become part of the written services and support plan, also known as plan of care.