Presentation for National Medicaid Congress

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Mini Summit- Dual Eligibles

Consumer Enrollment, Access, and Management Issues

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This presentation will be based on experiences with the 27-month effort in Massachusetts to implement a demonstration for 110,000 dually-eligible people with disabilities between the ages of 21 and 64. As of the submission of this document, rollout for the demonstration was slated as follows:

- Voluntary enrollment on July 1
- Passive/automatic enrollment on October 1

These dates are expected to be moved back, which will be the fourth such delay for an initiative originally targeted to begin on October 1, 2012. Of note is that passive enrollment for those in risk categories for people with complex needs will likely be delayed until some undetermined point in calendar year 2014.

There are a number of reasons for the delays, not the least being deep concern by Integrated Care Organizations (ICOs) around financing. Six were selected to operate the program in Massachusetts, but one dropped out because of the program's financial uncertainty and the other five have not signed contracts with the state and CMS. As with information on the start date, announcements on changes to the financing and risk adjustment are expected in the time period between submission of this document and its presentation.

It should be emphasized, though, that financing alone is not why the demonstration start-up has been delayed. Advocates in the state, notably Disability Advocates Advancing our Healthcare Rights (DAAHR), a coalition of over thirty disability rights groups, independent living centers, recovery learning communities, elder groups, healthcare rights organizations, and legal services agencies have pointed out many areas of the demonstration that need attention. DAAHR's regular dialogue with the state and CMS presumably has had impact, as have readiness reviews of the ICOs and their providers, which undoubtedly are showing gaps in networks and limitations on providers' cultural competency. It is often indicated that serving people with disabilities is different than serving non-disabled populations, but this characterization itself undersells the situation, because the disability population is actually

composed of many tremendously diverse elements with unique care and service needs, including people who:

- are homeless;
- have HIV;
- are substance abusers;
- have intellectual and developmental disabilities;
- are institutionalized;
- are blind or have limited vision;
- are deaf or hard of hearing;
- have a chronic illness such as diabetes, sickle cell anemia, or COPD;
- have significant mental illnesses such as schizophrenia or depression;
- have complex physical disabilities such as quadriplegia, ALS, and muscular dystrophy;
- have traumatic brain injury; and
- have combinations of any and all of the above.

Care for these populations is historically disparate, and other baseline characteristics such as race, gender, and sexual orientation create further disparities. Adding challenges is that Massachusetts will be integrating long-term services and supports (LTSS) with primary care, essentially an experiment that can produce more holistic, person-centered care and services, but one which also has major risks because the demonstrated experience of the ICOs with LTSS is extremely limited. In consideration of all of these factors, DAAHR has advocated for strong consumer protections, ones that should be in place before any broad implementation of the demonstration occurs. Specific protection elements include:

- *The right to opt out*: The state and CMS will allow consumers to opt out of the demonstration in any given month, an important right, though DAAHR continues to push for voluntary enrollment only; there are deep concerns that consumers will enter systems not able to meet their complex needs.

- *The establishment of the Independent Living Long Term Services and Supports (IL-LTSS) Coordinator*: DAAHR successfully advocated for every consumer to have access to an IL-LTSS coordinator on their care team. This will be an individual based at a community-based disability organization who will serve in an advocacy and information role for consumers around LTSS, strong recognition by CMS and the state on the importance of LTSS and the need to balance the primary care orientation of ICOs.

- *Development of quality metrics that incorporate the disability experience, including independent living and the recovery model of mental illness*: There are no widely accepted measures that address successful outcomes of care and services for people with disabilities, so DAAHR has sought new measures that speak to critical elements of the disability experience, including community integration, for which LTSS is critical.

- *Development of independent, consumer-based monitoring*: Objective analysis of metrics and trends in the demonstration, from a consumer perspective, are essential to determine if the demonstration is working and if consumers are getting services they need. A prominent concern is that care teams oriented to medical care will reduce LTSS such as personal care attendants for consumers, either because of unfamiliarity with these systems or because of pressures to achieve CMS savings targets.

- *Establishment of an independent ombudsperson program*: The state will soon be issuing an RFP for this basic consumer protection.

- *Establishment of an Implementation Council*: The state has supported creation of a consumer-driven council to collaborate with the state on key aspects of the demonstration implementation. This is intended to be more than a classic advisory committee, but as of this date its resources and the areas where it can intervene are not yet fully agreed upon. In many respects the council reflects the demonstration in general—great promise, but much still to be determined.

- *Cultural competency training for ICOs and providers*: The only broad trainings for ICOs to date have been provided by DAAHR after its receipt of a foundation grant to do this; more trainings supported by the state are slated to commence later this year. These are fundamental to ICOs and providers grasping the wide range of distinctive service and care needs of the duals population.

- *Ensuring compliance with the Americans with Disabilities Act*: CMS and the state are requiring ICOs and providers to comply with the ADA, an affirmative step strongly advocated by DAAHR. But this is going to take time, with need for ICO and provider staff training and review of policies, procedures, and facilities. It should be inconceivable for any entity wishing to promote better care and services for people with disabilities not to be fully proactive in ensuring equal access.

DAAHR has repeatedly said the Massachusetts Duals Demonstration is the best chance in a generation to get healthcare right for people with disabilities, and we have commended the

efforts of state officials and CMS. But it is a long road to positive change, and the undertaking will always present big challenges and risks for government and providers but most especially for anyone who may enroll in the new, integrated system of care. The duals initiative comes out of the Affordable Care Act. But similarities to coverage expansion for non-disabled populations are significantly superficial. Plans and strategies for duals demonstration implementation, most especially around timelines and scale of enrollment, must reflect the diverse and unique needs of people with disabilities, and at the core support inspired innovation with consumer protections. The demonstrations must truly be just that, demonstrations—not wholesale remakes of healthcare systems initiated under overarching pressures to cut costs.