

**“Don’t be left out in the cold”: Forum on MassHealth reform and Accountable Care Organizations (ACOs)
Hosted by Disability Advocates Advancing our Healthcare Rights (DAAHR)
January 14, 2016**

For clarification of anything in these notes or more information, please contact Allegra Stout at astout@bostoncil.org or 617-338-6665.

Summary of Presentation by Maggie Sheets of DPC:

ACOs— Groups of health care providers who contract with a payer to meet benchmarks, coordinate care, reduce costs—are coming to MassHealth. These will include coordinated care teams for consumers. The major questions are:

- a) Who will be on those care teams—just medical professionals or also LTSS coordinators, substance abuse providers, and mental health providers—and will individuals have the right to choose their own care teams?
- b) Who gets the dollars: Community based organizations like RLCs, or Big Hospitals and providers? Will there be easy access to LTSS, PCAs, transportation, and DME? Will there be housing supports?
- c) What does “accountable” mean? What will the standards be, who will set them, and will people with disabilities have a meaningful role in governance of these programs?

Action steps:

- *Join DAAHR’s advocacy
- *Tell us what is important to you
- *Tell your friends and family about upcoming changes
- *Talk to your providers
- *Attend stakeholder meetings
- *Contact MassHealth at MassHealth.Innovations@State.MA.US

Description of ACO plans by MassHealth Staff:

The goal is to break silos between primary care, mental health, LTSS. Current system is broken, especially for those with LTSS needs. They’re talking with CMS about linking payments to the 1115 waiver. They heard loud and clear that pieces of the care delivery system have been under-invested in, and they want to do more investment in community organizations, LTSS, and link them back to the medical community. Investment will act as a “catalyzer.” They plan to bring different kinds organizations together in ACOs for broad accountability—financial and patient outcome and engagement. ACOs won’t be one provider by itself.

In terms of populations, they heard feedback that given the challenge of integrating the medical side with LTSS and community orgs, formation of relationships needs to take time. Quality measures need to become more advanced. They intend to start with people in managed care and then gradually expand, including to dual eligibles. ACO accountability will only apply at first to services covered by MassHealth, not home care labor. In managed care, the number of RC2 and RC10 members is small. The guidance from the workgroups was to start small, at first on a reporting-only basis, and then start to cut costs gradually in year 2. They want to create more formal engagement between community organizations and ACOs, with a bifurcated funding stream—some straight to ACOs, some for infrastructure development including to community

organizations. They intend to be cautious, which is why they're leaving dual eligibles out to start with.

Q&A— Major question themes and responses from Mass Health

What's going to happen to the PCA program, which has been so successful? Will PCA needs evaluations be independent?

MassHealth response:

PCA is a vital service and MassHealth is now in the midst of implementing overtime and travel costs. No new news on PCA programs within the ACO structure. They're listening actively, want to be sure that all ACOs would understand the importance of the program. Their focus right now is on those in managed care, not on Dual Eligibles outside of it. Most PCA users would not be immediately impacted by ACO development, though it could expand eventually.

How will quality metrics be set? DAAHR should be involved. What's critically important to the people here is that the dollars don't just flow to the ACOs after year 1, and that there's evidence of quality improvement. How after one year will we have an evidence base, that hasn't happened with One Care? It's vital that community organizations are involved and get funding.

MassHealth Response:

Quality metrics are part of the quality strategy, which includes some things that may not be measured by metrics. Want to be realistic with time spent on collection of metrics, and focus on measuring reliable, well understood, actionable metrics. No measuring for the sake of measuring. We understand that some existing metrics are inadequate for the level of system change because we're moving forward into the future. We've talked to lots of individuals in lots of life circumstances. We don't want to go too fast, but we want to change the system. (also said she prefers "different ability" to "disability"). We aren't putting all our resources straight into ACOs. Community organizations like ILCs provide lots of services and will continue to get funding and be actively supported. We see these organizations as having a vital role in healthcare delivery. We're making provisions for the inclusion of community organizations and pushing hospitals and insurance companies to understand that. We want to be sure community orgs are instrumental to success of healthcare.

What about the problem with fixing acute care and the medical model? We aren't people who need to be fixed and are otherwise failures who get dumped into nursing homes. Locked up out of sight and out of mind. Most acute care people at large hospitals have little to no experience in long term care needs and never understand that people will need continued services indefinitely. We don't get fixed!

MassHealth Response:

From day 1 we've been very clear that we recognize that the resource allocation in the current system is not ideal. Avoidable admissions and readmissions and Emergency Department visits need to come down. Resource reallocation must happen.

Serious issues with Durable Medical Equipment. One attendee has had a broken chair for 1.5 months and had a broken bed for 6 months before using personal connection to MassHealth officials to get it addressed. Another can't get a dental appliance for sleep apnea considered

DME. Another couldn't get the \$300 roller walker she asked for, but MassHealth would spend \$5,000 on a wheelchair. DME needs to be personalized to individual needs. Accessible technology for autistic people should be considered DME—and iPads aren't the answer for everyone. Service dogs should also be considered DME; as-is, people train their own because it's too expensive otherwise.

MassHealth Response:

5 people mentioned DME, and we need to personalize it and get back to people quickly.

Housing is a huge healthcare concern. One attendee who works for a One Care ACO said 3/4ths of referrals are about housing. People aren't housed quickly for myriad reasons, including criminal history. Housing situation is the worst in 30 years. Almost 0% vacancy. People that are homeless are so difficult to care for. Supportive housing is especially needed. It's amazing how little there is. Most supportive housing isn't accessible, doesn't work for people with brain injury or dementia. Another was nearly left homeless (would have been but for help from friends) after contracting meningitis. His doctors never asked about housing, and he was told that his case wasn't impressive, that he was less likely to be housed because he wasn't a substance abuser, and that a person he just saw get housed had been waiting two years for a place.

MassHealth Response:

On housing, some supportive housing exists but there isn't enough. 1,500 chronically homeless people in MA, and we're trying to weave together housing and services to help them. There's a need for family housing and for affordability across the board.

Peer supports are vital. Why aren't there peers in place to talk to in the medical system? People respond to peer supports and it reduces anxiety and reduces need for doctors. Almost no peer respites in MA, which could be key to reducing high ER and ambulance costs, which are climbing even as other categories are flat or falling. One person said that being taken to a day program instead of the ER, where they stabilized her until she could move to a residential setting, saved her life.

MassHealth response:

Peer issue is one they've heard a lot. We want peers to be a bigger piece of service delivery. Key in emergency settings as was mentioned. MBHP embedding peers in housing process.

Other major points raised:

**Transportation like the RIDE is vital to health care. Transportation services provided through health plans are often poor. PT1 program is invariably late, leading to cancellations, and providers are rude. One attendee had her birth control changed to one that worked less well and caused serious side-effects because transportation couldn't reliably get her to appointments.*

**Medical facilities are often not fully accessible. Light and sound issues can cause lack of access for autistic people (including at this event).*

**We must hold to the ADA definition of effective communication. Lots of phraseology is meaningless. Intended recipient must fully understand what is being said. Be clearer. Traditional means of communication are not always enough.*

**Patient choice must be preserved, in terms of providers and services. Mental health services must be voluntary, and alternative treatments like acupuncture should be covered, especially for mental health.*

** In 2016, the 26th year of the Americans with Disabilities Act, no health plan for people with disabilities can be legitimate if it does not mandate accessibility and compliance with the law for health care services.*

**Mental health records must be kept private and away from general health providers unless the individual consents. Right now at many providers, any doctor with serious concerns can access them. This leads to demonstrably worse health outcomes for cardiac conditions, cancer, and pain. Mental health history might be used to refuse to admit people to drive down admissions.*

**There must be financial incentives for cost control, must be protected against economic decisions or we'll get 1990s HMOs all over again. Must be real appeal rights and advocate's presence on governance boards, and not just one.*

**People with disabilities and lived experience are the experts, and should be listened to and paid for their time.*

**Health providers must be culturally competent.*