



## Governor Signs Spouse Caregiver Study

On July 22nd, Governor **Charlie Baker** signed into law H.4499, which was enacted by the state legislature and put on his desk. Mass Home Care has been working on this legislation since 2008.

In outside section 181 of the FY 17 budget, state lawmakers adopted the following language, and gave MassHealth a homework assignment regarding spouses as caregivers:

“Not later than December 1, 2016, the office of Medicaid shall submit a feasibility report on the inclusion of spouses as a family member authorized to serve as paid caregivers to the clerks of the senate and house of representative, the house and senate chairs of the joint committee on health care financing and the

house and senate committees on ways and means. The report shall include, but not be limited to: (i) necessary state plan amendments and waiver applications required to allow spouses to serve as paid caregivers, which may include an application for a 1915(k) community first choice state plan option... (ii) anticipated state liabilities and expected federal financial participation, including an accounting of the office’s assumptions and figures used to calculate these liabilities; (iii) best practices and quality assurance measures; (iv) a comparison of other states that allow spouses to serve as paid caregivers; and (v) a proposed implementation schedule.”

When Outside Section 181 reached the Governor’s desk, he made a significant amendment. On

July 8th, Governor Baker issued a series of vetoes and amendments that changed a number of elder items from the budget—one of them was the spouse as caregivers outside section. The Governor recommended a one year delay for the spousal study due date from December, 2016, to December of 2017---giving MassHealth 17 months to do a study. In his message to the lawmakers, the Governor noted: “This reporting deadline does not provide sufficient time to complete this study and account for potential changes under the anticipated 1115 demonstration waiver.”

Mass Home Care opposed the delay, and told lawmakers: “A one year delay in reporting is not reasonable, given the fact that this option to allow spouses as caregivers has been available to the state for years, and the 1115 demonstration is being submitted this summer to the federal CMS. There is ample time before December, 2016 to submit the study requested, and there is no need to wait 17 months to prepare a study and develop an implementation plan. This plan could be prepared by the Executive Office of Elder Affairs, which is not responsible for the 1115 demonstration plan.”

preamble added on July 18th which read: “Whereas, The deferred operation of this act would tend to defeat its purpose, which is to provide for a feasibility report on the inclusion of spouses as paid caregivers, therefore, it is hereby declared to be an emergency law, necessary for the immediate preservation of the public convenience.” Ironically, after agreeing to delay the study, the legislature added a preamble that made the bill immediately necessary to implement.

The Governor had 10 to act on the measure, but he signed it after 4 days, issuing no press release. The report and implementation plan will not be due until December of 2017—17 months from now---if anyone in the legislature remembers.

Mass Home Care has said it will urge the Governor’s office to push the study’s timetable up, rather than run down the clock until the end of calendar 2017. Advocates have waited 8 years for the state to move beyond a study. According to Mass Home Care, a study of spouses as paid caregivers was part of the *Olmstead Plan* published by the Administration of Governor **Deval Patrick** in 2008. One of the goals in that plan, which is named after a 1999 U.S. Supreme Court decision that said disabled individuals have a civil right to be cared for in ‘the least restrictive setting’ appropriate to their needs, was to “study the feasibility of paying spouses as caregivers”---just like other family members.

The Patrick Administration set a date of December, 2010 to produce the spousal caregiver report—but no study was ever made public. Eight years of work has led full circle to a feasibility study and implementation plan which is still sitting on the Governor’s desk.

“This is a family friendly bill,” Mass Home Care Executive Director, **Al Norman**, explained. “Even the Veterans’ Administration allows spouses to be paid as caregivers. We are late to the party on this bill.”

The State Senate twice passed legislation that would have implemented spouse as caregiver, but the study and implementation plan was the furthest the concept could move this legislative session.

“We will push for an implementation plan,” Norman said, “and try to accelerate the 17 month study period.”

### *2008 Olmstead Plan*

The legislature chose to accept the Governor’s delay, and the outside section became a bill, H. 4499, enact by the legislature on July 15th, with an emergency



## Waiting Lists Expected After Home Care Budget Cuts

The FY 17 Conference Committee state budget released on June 29th cut elder home care funding by \$3,483,050 (-1.66%) below FY 16 levels. Mass Home Care raised concern that waiting lists could be required in the basic home care program, and in the Enhanced Community Options Program (ECOP). The latter is funded slightly above level funding in FY 16, but the enhanced program is roughly \$4 million below maintenance levels for FY 17. The basic home care program is \$2.02 million below FY 16 appropriations, and the ASAP care management account is \$1.75 million below FY 16 appropriations.

The Mass Home Care analysis suggests that the ECOP program will sustain a loss of 5.53% units per month. The number of elder clients will have to be reduced from 6,827 per month to 6,478 per month, a loss of 348.6 elders below current monthly levels.



In the basic home care program, a loss of 1% units per month will require elder clients to be reduced from 28,664 per month to 28,385 per month, a drop of 279 elders per month.

Advocates began urging state lawmakers to use a supplemental budget filed in July by Governor Baker as the vehicle to add more money to home care, using federal funds (see related story below). Mass Home Care also said that despite tight funding, the Executive Office of Elder Affairs should implement

the \$1.075 million ‘near poor’ pilot project included in the Conference Committee language for this account, which the Governor did not veto. The pilot is to serve ‘near poor’ elders whose income eligibility is within 15% of the home care eligibility limit, which is currently capped at \$27,014 per year. Elders with adjusted gross income of up to \$31,066 would be able to get home care supports. The home care program in FY 17 could be triaged to serve the elders with the highest unmet needs—including those slightly above the current income limit.

During budget deliberations, the House appropriated \$209.6 million for the total home care, enhanced home care, and care management/operations accounts, while the Senate appropriated \$210.7 million. In most budget deliberations, the House and Senate will either recede to one of the numbers already proposed, or come up a compromise number in between—but in this year’s Conference Committee an appropriation was chosen that was significantly lower than in either version, and lower than the Governor’s recommendation—\$206.9 million. The Conference Committee budget is a total of \$4.8 million short of maintenance levels for home care in FY 17, counting \$1 million for the pilot project.

On the positive side, the Conference Committee final budget directed EOHHS to “pursue, enhance and submit” 1915i and 1915k state plan amendments, created by the Affordable Care Act (line item 4000-0328 in the state budget). The state has been leaving millions of dollars in federal money on the table for years. These amendments, if filed, will claim those federal dollars.

As noted above, an outside section directed MassHealth to conduct a feasibility study of adding spouses as paid caregivers, and a proposed implementation schedule. This is long overdue reform.

In other action:

- Protective Services was the big winner: receiving a \$4.965 million increase (+21.5%) over the FY 16 appropriation.
- A \$200,000 elder mental health program was funded in a DMH line item to work with EOEA (5046-0000)
- The Council on Aging line item was loaded up with

\$807,000 in local earmarks, mostly for senior centers.

- Another big winner: nursing home supplemental rates rise by \$45 million over FY 16 appropriations.

Unfortunately, the Governor's vetoes issued on July 8th undid some of the progress made in the legislative budget::

- The Governor vetoed line item 4000-0328 so that MassHealth would not have to submit a 1915i and 1915k state plan amendment. This veto would result in a loss of more than \$19 million just in the 1915i amendment alone. But on July 23rd. the General Court voted to override the Governors' veto of 4000-0328, which means these state plan amendments will be submitted.

- The Governor vetoed the \$200,000 geriatric mental health line item.

The state legislature may take up more overrides before the formal session ends July 31st.

## Mass Home Care Files Amendment To End Home Care Wait Lists

On July 8th. Governor Baker filed an FY 17 supplemental budget (H. 4506) that included language changes in the basic elder home care services account. The Governor's language added federal Community First Trust Fund dollars to the home care services line item, 9110-1630--but did not change the bottom line.

In essence, the Governor used the federal dollars to replace existing state dollars. As a result, the home care system was still facing waiting lists for home care.

Mass Home Care prepared an amendment which increases by \$3 million the federal Community First dollars--but maintains the state appropriation, instead of offsetting it. This higher appropriation will prevent waiting lists in the home care account. The language reduces the percentage of state funds needed in this line item from 98.5% to 95.7%, and increases the federal percentage from 1.5% in the conference committee version, to 4.3%. The net impact is that federal funding is used to raise the basic home care account to avoid waiting list--at no new cost to the state beyond what the Conference committee recommended.

This amendment, which may be considered on

one of the special Saturday sessions the legislature has scheduled for the end of July, requires no additional money from the General fund. Rather, the amendment relies on federal dollars specifically targeted for home and community based long term care. The Governor's proposed language in the supplemental budget demonstrates that there is at least \$5.5 million in the federal Community Trust Fund that has not been committed yet.

## Advocacy Groups Testify On Need for 'Independent Agents' for LTSS

MassHealth Payment and Care Delivery Reform: Public Meeting



### *EOHHS Plan for ACOs*

A network of human services advocacy groups, including those for the elderly and individuals with disabilities, have told MassHealth that they want to see the state's Accountable Care Organization (ACO) proposal include "independent agents" for members who need long term care services and supports (LTSS).

On June 27, 2016, the President-elect of Mass Home Care, **Greg Giuliano**, who is the Executive Director of Montachusett Home Care, submitted the following statement to MassHealth regarding the need for "independent LTSS agents" in the proposed Accountable Care Organization 1115 Demonstration plan being submitted to the federal Centers for Medicare and Medicaid Services (*see July, 2016 At Home*):

"MassHealth has been given ample evidence that there is widespread support among community-based organizations who work with the elderly and

disabled for the ACO plan to include an “independent agent” for LTSS on the interdisciplinary care team:

- On October 1, 2015, 112 community-based groups sent a letter to Governor Baker saying “Whatever plan emerges from the MassHealth reform discussions, we urge you to guarantee that all managed care organizations covering LTSS provide as a standard benefit for their members access to independent conflict-free care coordination.”
- On December 7, 2015, Disability Advocates Advancing our Health Care Rights (DAAHR) sent MassHealth a letter asking that the ACO plan “protect consumer choice by including...an independent, conflict-free case manager or service coordinator for all enrollees in ACOs and health homes.”
- On March 10, 2016, 1199 SEIU presented MassHealth with a statement endorsing the need for an “independent Long Term Support Services Coordinator..mirroring language from MassHealth’s recent One Care demonstration proposal that establishes a LTSS coordinator role.”
- The home care program (Ch. 19A, s4B), the Senior Care Options managed care program (Ch. 118E, 9D) and the One Care managed care model (Ch. 118E, 9F), all contain clear statutory language regarding the use of conflict-free coordinators.

There is a rich tradition in Massachusetts of ‘independent agents’ in the LTSS field. The Centers for Medicare and Medicaid Services (CMS) in their final rule regarding managed care plans, give states the flexibility to provide conflict free assessments and care coordination. I urge you to review the attached documents, and strengthen the role and responsibilities of the independent, conflict free agents as a consumer protection in the ACO plan.”

Along with Giuliano’s statement, Mass Home Care submitted an 11 page statement on the Accountable Care Organization plan that presented a model for how to implement conflict free care coordination in an integrated care plan, and concluded as follows:

“There are many thoughtful aspects of this plan that should commend it to CMS and to MassHealth members. Mass Home Care supports many of the design elements in this June 16th version of the plan.

We remain concerned that the post acute care aspects of the plan seem less thought out than the acute care components; that LTSS outcomes are not in place; that the role of the “independent agent” on the care team should be more defined and stronger; that the use of home care supports should be centrally included; and that enrollment in the PCC plan should not leave members with costlier, second class inferior care.



In a related action, 29 consumer rights groups—including Mass Home Care--sent a letter to MassHealth on the ACO demonstration plan. In that letter, which was coordinated by Health Care For All Massachusetts, the advocates wrote: “We appreciate that MassHealth envisions an interdisciplinary team that includes a LTSS representative for members with LTSS needs. We seek clarification on this role, and urge MassHealth to ensure the LTSS representative truly has an independent voice in the care team, and offers a level of coordination similar to that provided by the LTSS Coordinator in One Care or the Senior Care Option’s Geriatric Support Services Coordinator.”

Similarly, on July 15th, the group Disability Advocates Advancing Our Health Care Rights (DAAHR), submitted its comments to MassHealth, which included the following area of concern:

“Conflict-free case management not established – ACOs that operate direct LTSS services should not be permitted to perform functional assessments in determination of LTSS. The magnitude of the task of

protecting against conflict of interest within ACOs is daunting and has the potential to continue to silo populations into specific delivery systems by diagnosis or category (i.e. behavioral health or developmentally disabled). There needs to be definitive establishment of conflict-free case management.”

The first recommendation from DAAHR to strengthen the ACO proposal called for a stronger role for community-based groups:

“The development of Community Partners (CPs) is a major part of the 1115 Waiver application. DAAHR is very supportive of providing DSRIP funding to support capacity building for CPs, especially so they can work with ACOs on the integration of behavioral health, long-term services and supports and health-related social services. DAAHR is concerned, however, about the lack of detail in this plan.



- **Concern:** The 1115 Waiver Application does not set forth clear and concrete criteria for CPs to meet before becoming eligible for funding. Moreover, the application favors ACOs over CPs in terms of the potential to realize gains from risk sharing. ACOs will include significantly large health care systems and hospital systems that will be allowed to benefit from assuming financial risk for the total cost of care for their attributed members. CPs, on the other hand, will not enjoy any upside risk sharing that can be used to build a stronger program model.

- **Solution 1:** DAAHR requests that MassHealth develop criteria for CPs in conjunction with disability advocates to create a framework for upside risk sharing for CPs, as well as an opportunity for CPs to participate in the governance of the ACO.

- **Solution 2:** MassHealth should provide prescriptive

guidelines to ACOs on the establishment of CPs to prevent ACOs from building CPs off of existing hospital community partnerships rather than establishing relationships with community-based organizations that have historically served the community. This includes ILCs, ASAPs and Recovery Learning Communities (RLCs).

The second recommendation from DAAHR addressed the need for independent LTSS agents on the interdisciplinary care teams;

“The 1115 Waiver application establishes an “LTSS Representative” position as part of the ACO structure. DAAHR appreciates the mention of this new position, but – lacking any detail – finds it difficult to understand how this may help consumers.

- **Concern:** DAAHR is concerned that the ACO LTSS representative may have a more limited role than either the IL-LTSS Coordinator in the One Care program or the Geriatric Services Supports Coordinator (GSSC) in the Senior Care Options (SCO) program. This would undermine the trust of the disability community and the value of the role to the member’s care. IL-LTSS Coordinators and GSSCs are essential to shifting the balance away from the medical model to the independent living and recovery models.

- **Solution:** DAAHR requests that the 1115 Waiver Application require that MassHealth establish an LTSS Coordinator position that has the same status that the GSSC has under the SCO program, engaging in discussion with disability advocates on specific aspects of the position. ”

## MassHealth Seeks Private Agency To Manage Fee For Service

MassHealth is looking for a private agency to help it manage its fee for services programs. This is in keeping with the agency’s efforts to shift management for health and long term care to private health plans, known as Managed Care Organizations and Accountable Care Organizations.

In July, the Executive Office of Health and Human Services (EOHHS) issued a Request for Responses (RFR) for a Third Party Administrator

(TPA) which it hopes to have in place by November 1, 2016. Only entities which have experience being a TPA can apply.

The Contractor will assist EOHHS with the administration of the MassHealth state plan LTSS services---but will not be responsible for Home and Community Based waiver services or for LTSS services delivered to MassHealth Members who are enrolled in Senior Care Organizations I(SCOs), One Care, and PACE plans. Members who will be covered by the TPA will include people enrolled in the Primary Care Clinician (PCC plans), Managed Care Organizations (MCOs), and MassHealth Members with MassHealth coverage and Medicare who are not enrolled in the SCO, One Care or PACE programs and are receiving MassHealth services on a fee-for-service basis. The TPA will oversee services for MassHealth Members who are 65 or over and eligible for MassHealth, but not on Medicare; MassHealth Members who are participating in an HCBS waiver, but are not otherwise enrolled in a SCO or One Care, will be covered by the TPA. There are 10 home and community based waivers in Massachusetts, one of which, the Frail Elder Waiver (FEW) is managed by the Executive Office of Elder Affairs.



“Given the significant care needs of the population eligible for state plan LTSS,” EOHHS wrote, “the complexity of the service delivery system for such LTSS, and the state’s desire to improve the quality, appropriateness and efficiency of LTSS, EOHHS is issuing this Request for Responses (RFR) in order to obtain the services of a Third-Party Administrator (TPA) to support EOHHS’ capacity to effectively administer LTSS services to eligible MassHealth Members. The TPA will not replace functions

performed by state employees or redesign provider networks or change payment rates. The TPA is also not intended to add new capacity to replace MassHealth’s Medicaid Management Information System (MMIS). The primary purpose of the LTSS TPA is to streamline, augment, and align administrative functions.”

Massachusetts is seeking a TPA to assist it in managing the following services, when delivered through MassHealth’s Fee for Service provider network: Adult Day Health, Adult Foster Care, Chronic Inpatient Hospitals, Chronic Outpatient Hospitals, Day Habilitation, Durable Medical Equipment, Early Intervention, Group Adult Foster Care, Home Health Agency services, Hospice, Independent Nurse (Private Duty Nursing), Independent Therapist, Nursing Facilities, Orthotics, Oxygen and Respiratory Therapy, Personal Care, Prosthetics, and Speech and Hearing Centers.

EOHHS said its goal was to seek an LTSS TPA partner who will work with EOHHS, EOEA, the state’s agents and vendors, LTSS Providers and stakeholders to:

- Improve the quality of services provided to LTSS Members;
- Expand the state’s administrative capacity to focus additional state resources on Provider engagement, program integrity, and quality improvement;
- Promote appropriate and efficient utilization of services by Members who need them;
- Streamline provider enrollment, credentialing, claims payment and other administrative processes in order to achieve cost-efficiencies; and
- Identify and leverage national best practices in LTSS administration to assist EOHHS deliver a best in class LTSS program to MassHealth Members.

Some advocacy groups have raised concerns that the TPA will be responsible for prior authorization for LTSS in the community, and could stretch out the approval process, which needs to be done in a timely way. Concern has also been expressed that a TPA could be a rationing tool to reduce services to people who require costly care plans. On the other hand, it is clear that MassHealth has been challenged to track LTSS care across programs, and keep on top of billing issues across programs.

## Auditor, MassHealth Disagree Over Personal Care In Rest Homes



*Suzanne Bump, Auditor. wwlp photo.*

The State Auditor's office released in July a report on the Adult Foster Care (AFC) and Group Adult Foster Care (GAFC) programs. Auditor **Suzanne Bump** took issue with payments to people in "LTC facilities."

In FY 2015, MassHealth paid healthcare providers a total of \$13.6 billion, roughly half of which is reimbursed by the federal Medicaid program. MassHealth spending account for roughly 38% of the state's total annual budget

According to the Auditor's press release, over a five-year period, "MassHealth inappropriately paid \$15.2 million for adult foster care (AFC) and group adult foster care (GAFC) services for members in long-term care facilities (LTC), which is prohibited by MassHealth's own rules."

The AFC and GAFC programs provide assistance with activities of daily living, including eating, dressing, laundry, and meal preparation, to elderly and disabled MassHealth members, which allows those members to continue to live independently in a community-based setting, and thus avoid the high costs of paying for those members to live in a long-term-care facility, such as a rest home.

The audit found that in 2013, MassHealth issued a letter to AFC and GAFC providers informing them that, despite guidelines to the contrary, it would pay for

GAFC services for individuals in LTC facilities rest homes) until it could enact regulations for the GAFC program. This letter stated that although MassHealth "does not allow GAFC services to be delivered to members living in Rest Homes, Group Homes [or] nursing facilities," it would nonetheless continue to pay for these services for members in LTC facilities. An email sent days later clarified that MassHealth would also pay for these services for any new members living in LTC facilities. Three years after the letter and subsequent email, Masshealth has still not enacted regulations and thus continues to pay for these services."

"Essentially, MassHealth created and sustained a loophole that allowed GAFC providers to receive inappropriate payments," the Auditor said. "When MassHealth pays for GAFC and long term care services for a single member, it is in-effect, paying for 26 hours of care each day for that member," Bump said of the practical impact of these inappropriate payments. "When agencies make informal policy decisions, such as this letter and email, that contradict existing guidelines, it creates confusion and uncertainty, and provides opportunities for inappropriate payments that cost taxpayers money."

The audit found that 80% of the improper payments were made to seven GAFC providers at 20 rest homes. One owner of a GAFC provider received more than \$1.3 million in improper payments for MassHealth members residing in a rest home he also owned. During the audit period, MassHealth paid approximately \$1.3 billion for AFC and GAFC services for 30,408 members.

94% of the claims problems were in the Group Adult Foster Care program--but the audit clearly shows that providers were doing nothing wrong, just following MassHealth guidance.

MassHealth told GAFC providers in 2015 that if they were providing services to people in rest homes, they could continue to do so, for existing and new clients. The Auditor is not placing blame on the providers in this audit, but is asserting that MassHealth needs to clarify its policy and not allow people in rest homes to get GAFC supports. No fraud was committed, because GAFC agencies were operating in conformity to MassHealth instructions.



## Mass Home Care Comments On Rules For Community Care

On August 3rd. Mass Home Care, which represents the Area Agencies on Aging and the Aging Services Access Points in Massachusetts, is slated to present testimony on the “Massachusetts Statewide Transition Plan for Compliance with the CMS Home and Community-Based Services Community Rule.”

The federal government requires all states to review their community services to make sure that are in compliance with the Center of Medicare and Medicaid Services (CMS) Final Rule of home and community based services. The state’s revised State Transition Plan plan, dated July, 2016, covers the 10 home and community-based MassHealth waivers currently operating in the Commonwealth. Mass Home Care’s remarks Our remarks focus on the Frail Elder Waiver (FEW), waiver number MA.0059, operated by the Executive Office of Elder Affairs.



MassHealth state plan services, and the Frail Elder Waiver (FEW) have several design flaws, Mass Home Care says, that significantly limit the ability of elder consumers to have “full access to benefits of community living and the opportunity to receive services in the most integrated setting appropriate,” as called for in the CMS Final Rule on Home and Community Based Services.

The stated purpose of the FEW is as follows: “Many elders who are nursing facility eligible prefer to remain in their homes in the community when sufficient supports can be put into place to maintain them safely in this setting. The purpose of the Frail Elder Waiver is to make such supports available to frail elders, aged 60 and older who have been determined through an assessment process to meet a nursing facility level of care and require supports to reside in the community.”

The plan says “the nature of the FEW is to keep participants in their homes...” Yet the plan does not address the fact that all other waivers in Massachusetts offer members the choice of 24/7 residential supports with services.

The state plan says that for every service in the FEW, the service should “optimize interaction, autonomy, and independence in making life choices,” and “the services facilitate choices regarding supports and who provides them.”

Mass Home Care in its testimony recommends 5 changes in the FEW that will “expand choices regarding supports and who provides them” :

1. Add a 1915i and 1915k state plan amendment to broaden the “full access to benefits of community living” for elders on MassHealth.
2. Add 24/7 residential with supports (residential habilitation) to the 1915c Frail Elder Waiver, which is the only waiver out of 10 waivers in Massachusetts that does not offer participants 24/7 residential supports as an alternative to nursing facility care.
3. Allow self-directed care as a service delivery option.
4. Allow spouses to be paid caregivers under the FEW, as well as 1915i and 1915k
5. Make independent agents a standard feature of service plan development in all 10 waiver programs

Mass Home Care believes that if these 5 changes were integrated into the FEW, the elderly waiver would be much more compatible with the CMS Community Rule, and would provide services to members that enhance their choice and independence in the community.

## Aging Network Facing Life Or Death Choices

In a recent column posted on the internet by the Altarum Institute, which is a nonprofit health systems research and consulting organization that integrates independent research and client-centered consulting to create comprehensive, systems-based solutions that improve health, the head of the federal Agency For Community Living (ACL), which oversees the Area

Agencies on Aging—including those in Massachusetts, warned that the aging networks are facing some “life or death” choices.

Assistant Secretary for Aging **Kathy Greenlee** was addressing the National Association of Area Agencies on Aging (n4a) at its spring policy conference. President **Barack Obama** had just signed the Older Americans Act (OAA) reauthorization into law a week earlier—the culmination of a six-year effort. This is the major federal funding for the Aging Network, the community-based supportive services that many elderly people need in order to live at home with the limitations associated with age and illness. While many among the assembled Area Agency on Aging (AAA) representatives seemed inclined to reflect on and celebrate this achievement, Greenlee was already looking ahead. Noting that the current reauthorization of the OAA covers just three years—through FY 2019—the Assistant Secretary urged attendees to begin thinking in broader, bolder terms right away. “We need a major revision to the Older Americans Act,” she declared.



*Kathy Greenlee, Assist Sec. for Aging, ACL*

According to the Altarum blog, figuring this out, Greenlee acknowledged, will “be very hard.” To begin, she said that providers of community-based supportive services have to “be more willing to agitate” and to think creatively about how to restructure the

relationship between the medical care and community services sectors. Greenlee observed that the Centers for Medicare & Medicaid Services (CMS) sees Medicaid as a “natural partner” for the Aging Network, but “in a Medicare world they don’t see that at all.” This plays out, she noted, in a “huge loss of opportunity” with regard to Medicare-financed post-hospital care—use of which she said should be “a signal that care transitions are needed.”

To change the dynamic, Greenlee suggested that the Aging Network could “start with home care and skilled nursing facilities” and “talk to Medicare” about community-based “activity and functional support needs.” She asked attendees to consider, “Who are our champions in the medical world? We need to take doctors with us to these meetings to help make this case.”

Altarum supports ideas for the next OAA reauthorization as advanced by the Leadership Council on Aging Organizations in 201, including:

- “demonstration projects to assist AAAs and Aging Disability Resource Centers (ADRCs) to extend their expertise in supportive services planning and delivery to health/medical care entities that are involved in developing new models of care coordination”;
- “an Advanced Aide training curriculum for direct-care workers” and a new requirement for “state and area plans to...monitor direct care workforce supply and standards”;
- development of area “housing with services” plans;
- “greater collaboration” between the Administration for Community Living (ACL) and the Department of Transportation; and
- a “technology development program to...improve service delivery and more effectively track and report on OAA programs and services.”

To better address the challenge of scaling critical home-based services for millions more older adults both now and over the next few decades, Greenlee called for enhancing the Aging Network’s “flexibility” with regard to eliminating certain “silos.” One piece of additional flexibility that is needed, she said, concerns OAA-established planning and service areas (PSAs): “We have to change the restriction” that AAA’s “can’t also provide direct services” in PSAs, Greenlee

asserted, adding that, as currently constructed, these areas are “too limited” for the “fluid nature of what we need to provide.” The OAA constrains the ability of individual AAA’s to deliver OAA-funded services in their own service area.

Greenlee characterized ACL’s Business Acumen project as a “matter of life and death” for the Aging Network, which has a mission to serve all elders in need in the community. Calling for a more proactive approach to expanding and scaling services, she noted that if existing AAA’s are not successful in contracting with health care organizations, “others will be.” Because “there will be competition” from new services providers that do not have a community mission, Greenlee urged advocates and allies to “watch the competitors...where do they pull things out of the Network?” And “what are they not doing?” In an important move to help extend and expand the Business Acumen initiative, the John A. Hartford Foundation recently awarded \$2.9 million to n4a for development of a national aging and disability resource center, which is charged with providing technical assistance to AAA’s and partnering with community-based organizations that are seeking to partner with medical care providers.



The Aging Network’s lack of health information technology (HIT) infrastructure remains a significant barrier to this work. “We have significant trouble with technology,” Greenlee said. “No one is investing in our technology.” She cited the example of San Diego County, which received a grant through the Community-based Care Transitions Program (CCTP) and then found

that communicating with hospital partners and CMS effectively required an investment of \$284,000 in order to develop an HIT system. While San Diego was able to secure these funds, other CCTP sites did not have the resources to make a similar investment, causing Greenlee to wonder aloud, “Did CMS understand we don’t participate in meaningful use?”

An Affordable Care Act demonstration, the CCTP was designed to link individuals at high risk of hospital readmission with Aging Network services providers using evidence-based care transition protocols. Although successful CCTP sites calculate that they saved over \$800 million in avoided Medicare hospital costs across all successful CCTP programs, CMS is ending the program this year. Some of the Massachusetts based Aging Services Access Points, which led these efforts with their hospital and physician partners, produced some of the best outcomes in the country.

Without a substantial investment in HIT that is designed for the Aging Network’s social services and supports, Greenlee said, AAA’s and their contracting community-based organizations will have difficulty communicating with medical providers using electronic health records, and they won’t get appropriate credit for the outcomes of evidence-based chronic disease management programs that they conduct. For example, Greenlee observed, “the doctor needs to know” what a diabetes self-management program is doing for his or her patients, and the same applies to falls prevention and many other chronic disease programs that are designed to empower and assist seniors to live safely at home.

New metrics are also needed for tracking and reporting “service consistency and service delivery.” This too requires investment in HIT. The Assistant Secretary noted, the “OAA is built on output [e.g., number of meals served], not on [individual health] outcome, and we live in an outcomes world.” To change this rapidly, and to start capturing reliable data on the impact of social services and supports for vulnerable older adults and overall care costs, requires a dedicated “investment in community-based technology.” Absent this, she predicted that the health care system will continue to “build closed systems” that will bypass

communities and social services providers.

The Altarum Institute says that social determinants of health should have equal standing alongside medical care. A new infrastructure is needed, Altarum says, to capture person-focused information efficiently in an easy-to-access online format that is accessible to the older adult and family members, and which is also available to relevant service providers for amending and updating.

## Gawande Tells Congress: Just Living Longer Is Not The Goal



*Dr. Atul Gawande, Mass Home Care photo*

On June 23, 2016, **Dr. Atul Gawande** testified before the U.S. Senate Special Committee on Aging on serious illness. A general surgeon at Brigham and Women's Hospital in Boston, Dr. Gawande is the author of the best-selling book, *Being Mortal*. Here are excerpts from Dr. Gawande's remarks to Congress:

"People with serious, potentially life-limiting illnesses face substantial and increasing suffering, particularly during the last year of life. Medical care today typically exacerbates this suffering, often without any benefit of lengthened life. We have a major opportunity to change this, however.

People have priorities in their lives besides just living longer. These priorities are individual and change over time. The most effective and important

way to learn these priorities is to ask people. But we ask less than one-third of the time before people die. When we don't ask, the result is suffering, for care and treatment often ends up out of alignment with what matters most to individuals. When we do ask, and align our care with their priorities, the results are remarkable. People experience more control over their care, less anxiety and depression, more time at home and with family, and lower costs, and they do not have shorter lives. On average, in fact, they live longer.

Our goal therefore must be to assure all Americans that when they face a serious illness, their care will honor their personal goals and priorities. Achieving this requires ensuring that:

1. Everyone 18 or older has designated a health care decision-maker (health care proxy);
2. Everyone 18 or older has had a conversation (and continues to have conversations) with their proxy to communicate their goals, values, and preferences for care at the end of life;
3. All clinicians have appropriate training to facilitate high-quality communication with patients on advance care planning and serious illness;
4. Everyone facing a serious illness has had a high-quality, informed goals and values conversation with their care team;
5. All health care providers have systems in place to elicit and document goals, values, and preferences for patients with serious illness;
6. All health care providers have systems in place to share patient goals, values, and preferences across care settings, to ensure they are accessible regardless of place of care.

To achieve these goals, we need a concerted campaign and federal support to assure:

1. That we track progress on these goals, and on the outcome of improving the wellbeing of people with serious illness.
2. That we have a clinical and elder care community with better systems and skills for discussing serious illness care goals and priorities with individuals and their families.
3. That we devote research resources to science that improves our therapies and our systems for increasing the quality of life, and not just the quantity of life, of

the seriously ill.

In studies of people with terminal cancer, clinicians ask about their goals for the last phase of their lives less than one-third of the time before they die. Families appear to do little better. And when we do ask, it is generally not until close to the very end.



Partly, this is because we clinicians are uncomfortable having these conversations until all uncertainty is removed about what is happening and when. Partly, we often fail to recognize that the amount of suffering that people endure in their last year of life, even well before the end, is considerable. Surveys reveal, however, that during their last year of life, half of patients are often in moderate to severe pain and experience at least a month of depression, periodic confusion, difficulty breathing, and incontinence. Worse, between 1998 and 2010, the percentage of people experiencing pain, depression, and periodic confusion actually increased. Medical care for the symptoms people experience at the end of life does not seem to have gotten better; it may have gotten worse...

There is increasing evidence about what the content of these discussions should be. At Ariadne Labs, our research center at Brigham and Women's Hospital and the Harvard Chan School of Public Health, we have developed a serious illness conversation guide for clinicians based on the evidence. It identifies critical questions for clinicians and families to discuss in order to identify one's goals and priorities for care:

1. What is your understanding now of where you are with your illness?
2. How much information about what is likely to be ahead with your illness would you like from your doctor?
3. If your health situation worsens, what are your most important goals?
4. What are your biggest fears and worries about the future with your health?
5. What is the minimum quality of life you'd find acceptable?
6. If you become sicker, what are you willing to go through, and what are you not willing to go through, for the possibility of gaining more time?
7. How much does your family know about your priorities and wishes?

In my state, we recently launched the Massachusetts Coalition for Serious Illness Care with the mission of ensuring that every resident receives health care that honors their goals, values, and preferences. Achieving this requires that people across the state have critical conversations about their goals and wishes in the event of serious illness long before crisis comes. After all, seventy percent of those who require end-of-life care decision making will be unable to make those decisions for themselves. If someone else is to make these decisions, they have to know how to be faithful to our wishes.

In order to track our state's progress, the Coalition has planned an annual statewide survey of people's attitudes and experiences related to serious illness and end-of-life care. Results from our initial (March 2016) baseline survey reflect what national surveys have indicated—we have a lot of work to do:

- 85% of respondents believe that doctors should discuss end-of-life matters with patients, yet only 15% have ever had such a discussion.
- Only 25% of those facing a serious illness have had a goals conversation with their doctor.
- More than half have not named a health care agent to make decisions when they can't.
- Men, minorities, and those with less than a college education were significantly less likely to have named a health care agent or discussed their end-of-life care wishes.

• Almost one-third of those surveyed had lost a loved one in the past 12 months, and of those, more than one third felt that their family member's wishes were only partly followed, or not at all...

If there is any single, consistent lesson that I learned in my research for my book *Being Mortal*, it was that people who face serious illness or infirmity fear more than anything losing their autonomy—their ability to control the purposes and parameters of the care that they receive. Care plans and quality measures for nursing homes and other settings, however, focus almost exclusively on narrow issues of health and safety like fall prevention, management of feeding tubes, nutrition, pressure ulcers, and so on. These are important.



But just as, if not more important to people who need help with their needs for day-to-day living is the ability to have a say over matters like privacy, the risks they are permitted to take, when they go to bed and when they wake up, how they furnish and decorate their rooms, opportunities to pursue purposes larger than just mere existence, and who will make decisions when they cannot.

Similarly, in acute care settings, there is little recognition that care should focus not only on improving survival but also on supporting the ability to pursue those purposes and aims that matter most to individuals. We publicly report survival rates for particular conditions and measures for preservation of health and safety, but we do not have measures that ask how effectively care supports wellbeing. People have reasons they wish to be alive, but in our incentives and

expectations for health care and elder care, we don't seem to acknowledge that at all...

My investigations made clear to me that we've been unclear about the goal of good care for people with unfixable problems. It is not mere bodily survival. Nor is it a good death. The goal is to have as good a life as possible all the way to the very end.

The evidence indicates that we in the medical profession harm vast numbers of people by neglecting this goal. People with serious illness have essential needs aside from just living longer. Medical practices, research, and policies must ensure that clinicians have the skills to understand those needs and the ability to serve them.

Because death is not an inherent failure. Neglect, however, is."

## One Care Plan Extended Through 2018

On July 21st, MassHealth announced that the One Care program has been extended by the federal government:

"MassHealth is thrilled to announce that on July 5, 2016, MassHealth, the Centers for Medicare & Medicaid Services (CMS), and the One Care Plans executed an addendum to the Three Way Contract that extends the demonstration period for One Care through December 31, 2018."

According to MassHealth data, One Care enrollment after 2.75 years (as of June, 2016), was 13,038 members--about the same level it was at in April of 2014. A total of 30,028 MassHealth members have chosen not to enroll in One Care, or roughly 29% of the people who are eligible to join. The enrollment of 13,038 is roughly 12.6% of the 103,041 eligibles on MassHealth, which means 87.4% of those eligible are not in the program. MassHealth also announced that it is looking for more insurers who want to become One Care plans.

25% (3,220) of the members in One Care do not have high community needs, or high behavioral health needs. 77% of all enrollees are in Commonwealth Care Alliance, and 23% in the Tufts Health Plan.