

Governor's Council to Address Aging in Massachusetts

Monday, October 2nd

3:00 PM - 5:00 PM

McCormack Building

One Ashburton Place - 21st Floor Conference Rooms 1 & 2

Boston, MA 02108

In attendance: Co-Chair Eileen Connors; Secretary Rosalin Acosta, Secretary Alice Bonner, Bill Caplin, Joe Coughlin, Rosanne DiStefano, Beth Dugan, Kevin J. Dumas, Assistant Secretary Fichter, Betsey Hampton, Steven Kaufman, Undersecretary Chrystal Kornegay, Nora Moreno Cargie, Tom Riley, and Amy Schectman.

On the phone: Gerard Brophy, Laura Iglesias Lino, Brian O'Grady, and Janina Sadlowski.

Not present: Co-Chair Secretary Sudders, Tom Grape, Ruth Moy, and Alicia Munnell.

Guest Speakers: Tom Cahir, Zach Hughes, Aniko Laszlo, Mary Jane Pacheco, and Anne Tumlinson.

Council Staff: Anna Kennedy, Andrew Kim, Robin Lipson, William Travascio, Patricia Yu, and Olga Yulikova.

The meeting was called to order at 3:01 pm by Secretary Alice Bonner, who welcomed all Council members and visitors. A motion was made by Amy Schectman to approve the minutes from the September 7th meeting. The motion was seconded by Tom Riley and the minutes were unanimously approved.

Secretary Bonner briefly introduced panels on caregiving and transportation. She highlighted that these two areas were frequently identified as important issues during the listening sessions and in comments through the online portal. Secretary Bonner outlined that the final 10 minutes of the meeting would be dedicated to discussing emerging thoughts around recommendations as the Council looks forward to the December meeting, which is the last meeting of 2017. Secretary Bonner turned the microphone over to Co-Chair Eileen Connors, who welcomed the panelists and expressed excitement about what they would share.

Tom Riley provided background information on caregiving and noted 2 handouts that highlight some statistics about caregiving. This research was conducted in conjunction with AARP. Caregivers spend significant numbers of years caregiving (about 5 years on average); unpaid care is estimated at \$470 billion per year nationally. There are over 44 million caregivers—the majority of whom care for someone older than 50. In Massachusetts, 726,000 caregivers care for approximately 940,000 older adults and provide 786 million hours of unpaid care, valued at \$11.6 billion. 332,000 individuals in Massachusetts are supporting individuals living with Alzheimer's and other related Dementias, providing 378 million hours of unpaid care, valued at \$4.6 billion.

Next, Tom Riley introduced members of the Caregiving panel:

- Anne Tumlinson, CEO/founder of Anne Tumlinson Innovations, LLC and Daughterhood.org**
- Mary Jane Pacheco, Family Caregiver to her Mother, Cecilia Pacheco**

Mary Jane Pacheco shared her experience in caregiving. At the age of 14 she volunteered in local hospitals. She explained that volunteers were known as ‘candy stripers’ because of the colors of their uniforms. At 19 she became a Certified Nurse’s Assistant and worked in many nursing homes. Mary Jane became a private duty aide when there was a woman who asked her if she could take care of her in her home. This woman lived another 5.5 years despite a 2-week prognosis. After her client passed away, Mary Jane went on to have meaningful caregiving relationships with several other clients.

Mary Jane began to care for her mother Cecilia in 2012, when the family became concerned about potential neglect with Cecilia’s current living situation. She was hospitalized for malnutrition, diabetes and several other conditions, and Mary Jane subsequently admitted her to a nursing home. There her mother was diagnosed with dementia. Mary Jane left her job and spent every day with her mother. When the nursing home where her mother was living closed, Mary Jane brought her mother home to live with her, which she said was the most rewarding experience of her life. Cecilia lived with Mary Jane for three and a half years. Every now and then, she would be hospitalized but would always come home to Mary Jane’s care—Mary Jane did everything for her. On July 21st, 2017 after being in a home hospice program following a heart attack, Cecilia passed away.

Anne Tumlinson thanked Mary Jane for sharing her story, and noted what a privilege it is to be invited to the Council. She has spent most of her career studying the U.S. aging and senior care system. About 4 years ago, she had a midlife crisis inspired by a family situation—Anne thought she knew exactly how Medicare worked, but realized she had no idea. She quit her high-profile consulting job and did research and writing on family caregiving. She outlined her presentation as information gathered at the local level through the Daughterhood.org organization she created. The organization’s mission is to help people feel less alone. Anne referenced Roz Chast—a cartoonist and advocate—as describing the caregiver experience as, “a country I didn’t even know existed, even if you’re an ‘expert.’”

Anne’s points continued:

- Family caregivers have an incredibly broad and deep sense of responsibility. When thinking about frail older adults, people generally envision a nursing home. In fact, two thirds-three fourths of that demographic are living at home, and at least half are cared for by family caregivers. What do the caregivers do? Everything--business, social work, law, etc. Hands on activities of daily living, navigation/care management within the incredibly complicated health care system. Caregivers have to do things that “make nurses squirm.” When asked “what do you struggle with?” it’s about getting parents to do what they need to stay safe, and dealing with complicated sibling dynamics in the midst of this.
- There is a lack of information, support, training, help, and community available to caregivers (caregiving is its own ‘professional’ domain in and of itself). To do hard things *alone* is what makes it *really* hard. How do you learn how to do these complex tasks, who do you turn to, how do you pay for it? This is an impossibly huge job put on families, and they have no tools.
- There are huge costs. Many women have had their relationships fall apart. Caregivers experience their physical/mental/financial health deteriorate, they aren’t contributing to their own savings at an incredibly crucial time in their lives, making the problem a vicious cycle for when they themselves get older. It’s also incredibly stressful for teenagers to be in homes with aging grandparents, financially and in terms of getting the attention that teenagers also need.

- Every state needs to develop a strategy to help caregivers stay at work and maintain their own financial security. Caregivers need information, training, and referral hubs to assist with knowledge. Concretely, business and government leaders need to come together to have explicit conversations about how to support the work of caregivers—and to include health care leaders in the discussion. Finally, states such as; Hawaii, Washington, Minnesota are working on how to pay to insure that caregivers do not continue to be left vulnerable.

Amy Schectman commented that she lost her mom one and a half years ago, and thanked Mary Jane for sharing her story. One of the things that Amy said that got her through this tough period in her life was Roz Chast's book *Can We Talk About Something More Pleasant?*. She will be a guest speaker at the upcoming JCHE Gala.

Secretary Bonner asked Anne to speak more about the emergence of getting started at the municipal level vs. state level---considering age-friendly communities and how communities individually support caregivers.

Anne Tumlinson expressed that she loves the age friendly movement. Many changes need to be made at the municipal level, in part because healthcare systems sit within communities. The interaction with those healthcare systems are so much of what caregivers do. The healthcare system must be brought into the conversation. The other challenge is that many caregivers are caring for people who are far away. A really good community support system will link to another caregiver support program in a distant region. Area Agencies on Aging – AAAs, play a very important role in this.

Co-Chair Eileen Connors thanked both of the panelists; she said that their information was helpful for the Council. Eileen asked Mary Jane about her biggest challenge in taking care of her mom.

Mary Jane said knowing her mother had dementia was her biggest obstacle. Mary Jane said that her mother knew who people were but she couldn't identify them. Later on her mother lost her ability to walk. Mary Jane said that being a caregiver is very emotional, she cried a lot, and was often alone. She also mentioned that there were physical challenges, like lifting her mother 15-20 times a day.

Anne Tumlinson said her biggest challenge was physical work, but also the emotional toll it took on her – specifically, having to make decisions for somebody else. The burden of wanting to make the right decision for somebody else's life, and personal identity being turned upside down - caring for the person who cared for you your entire life. And, the logistics of trying to work in the midst of the constant need to provide care.

Secretary Bonner asked what kind of a program would make a difference in the community for caregivers and older adults?

Nora Moreno-Carnegie brought up the need to discuss culturally specific communities. Are there organizations that can be tapped into to provide supports?

Anne Tumlinson said there are some organizations with that particular focus—for example, the Maria Shriver Foundation has begun to provide support for ethnically diverse caregivers providing support for elders living with dementia.

Joe Coughlin suggested three things to highlight in the Council's suggestions:

1. Technology—“there is an app for that,” the private sector needs to be engaged.
2. Aging/caregiving is far too big for government only. Need to focus on the private sector (ex: Best Buy can size up a home to see where technology innovation would help older adults).
3. Employers themselves could be a resource for primary knowledge on aging resources. He also pointed out that employers’ knowledge of these programs could help to mitigate the 50-80 billion dollars of lost production per year because of caregivers leaving the workforce.

Steven Kaufman asked Mary Jane that when she was caring for her mother, if there were people who she could reach out to support, who would she reach out to?

Mary Jane said she would reach out to her dad and her sister.

Brian O’Grady said that one place she could reach out to for help is her local Council On Aging. The COA can provide services or reach out to an agency that can provide services to the caregiver, such as; respite care, transportation, and assistance shopping.

Secretary Bonner asked Anne Tumlinson to provide a final word before moving on to transportation.

Anne mentioned organizations she works with consistently want to invent, innovate, and create new services. They run up against the problem that people may not even self-identify as a “caregiver,” and that MA is focused on getting people to understand what they are doing, understand resources, and incorporate technology only where useful.

Secretary Bonner noted that this area is one where the Council should make bold recommendations.

Joe Coughlin highlighted that transportation is far more than getting from point A to B; it is the glue that holds life together. It goes beyond “triage” around mobility. ‘Mobility’ is the desire to travel, which is growing more than ever. Every Council member wants to get out, with far more healthy life years. Most adults want to work, volunteer longer etc. More than 71% of adults live in rural areas where transit isn’t working. Many don’t include transportation as part of retirement planning. Retiring to the lake is great until you can’t drive. Another challenge is that less than 40% of assisted living facilities are within a half mile of public transportation. Driving focus needs to be on safety within chronic conditions, not age. Joe stated that, when viewing technology as the answer—there is a long road until driverless cars are a feasible solution. He suggested lifelong driver education. In his concluding remarks, Joe stressed the need to consider the implications of the primary alternative—riding with someone who does drive. Very few people want to ask a friend for an “unnecessary” ride. Accessibility doesn’t mean options are easy. Ride sharing services such as Uber or Lyft etc. should be part of the overall scenario, but not the only option. The “last 50 feet problem” of getting safely into where they need to be hasn’t been solved. Lastly, the Council must envision redesigning livable communities to be fun, accessible etc. What would success look like? Policy must think about outcomes. How would you get an ice cream cone on a whim on a warm summer night?

Kate Fichter, the Assistant Secretary for Policy Coordination at MA DOT, introduced Aniko Laszlo (Statewide Mobility Manager, MA DOT), Tom Cahir (Administrator, Cape Cod RTA), and Zach Hughes (Senior Operations Manager, Uber New England). To frame the conversation, Kate stated that there are certain ways in which transportation for the aging population is similar but also different from the rest of the population. There is tension between the concept of aging in community in low density suburbs/rural areas versus higher density metro areas. Transportation for older adults is different in

terms of driving capacity and the changing nature of the types of transportation accessible to older adults.

Aniko Laszlo previously worked at UMass Medical School under a grant from the Center for Medicare and Medicaid Services (CMS), with the objective of creating better employment opportunities for people with disabilities. Transportation was the issue that emerged as a barrier. In 2012-2013 Governor Patrick signed an Executive Order to investigate solutions—and the recommendation to the Governor was to bring together a state-wide network where smaller communities and regional stakeholders would communicate information back to policymakers. She noted that “life does not stop” at the boundaries of an RTA. There is a need to focus on individual experiences, and the power rests within communities to communicate individual needs of stakeholders. People need to know about “wraparound services” through travel training. In addition, MA DOT set up a program where RMV personnel travel to senior centers to talk about how and when to stop driving. MA DOT has also funded a statewide inventory of available services (ridematch.org). In some communities such as the Quaboag Valley, consumers are stuck between two RTA systems; the community came together to work with the RTAs, hospitals, etc. to put together the financial puzzle of how to make the service happen.

Secretary Bonner noted that this last comment about how the Quaboag Valley came together is an example of how to scale and build on what is happening already.

Tom Cahir - Administrator of Cape Cod Regional Transit Authority. Cape Cod wants to make transportation affordable, safe, and efficient. When the Cape Cod Times indicated there was inadequate infrastructure for transportation, housing, etc., Tom designated a staff member to go visit every Senior Center to listen to how they can better provide transportation services. As a result, several programs and adjustments were made, including free fare Wednesdays- which has provided thousands of rides over the past couple of months to elders. The initiative increased training within the councils, volunteer drivers, and created a Boston hospital bus. They have also expanded vehicle choices (smaller vans that don't require a specialized Commercial Driver's License or CDL). Cape Cod RTA also created a multi-mobility task force. Having provided 1.4 million trips throughout the region; Cape Cod RTA is excited about their model and best practices.

Zach Hughes has been a Senior Operations Manager at Uber for the past 4 years. He stated that there is tremendous potential in using Uber to solve transportation issues with older adults. Giving up one's car keys impinges on a sense of independence/self. Uber helps people preserve their independence—everywhere. People want to retire to the beach or golf course, and Uber can be at many beaches within 5 minutes. Making transportation more reliable is something the company is focusing on. Last summer, Governor Baker signed a ride sharing law, which has opened the door to public-private partnerships. An example of this is, the MBTA has sponsored a pilot where the first \$15 of a trip via Uber is subsidized through THE RIDE. Uber is looking to grow those sorts of opportunities. Another collaboration is with North Shore Community College - the school pays for rides for their students to get to and from the local T station, which is far from campus. Uber has also been talking with Mary McGinnis at Pioneer Valley Transit Authority about opportunities. Regarding technology solutions, Uber Central allows another person to book a ride for a loved one. Zach sees the aging community as one of the biggest areas for growth within Uber. Some residences in Florida have started using this service for their residents.

Roseanne DiStefano suggested an “Uber Central” to request rides from a specific 10-12 person team

of drivers (perhaps family members or close friends), making the service more like a personal care attendant. A driver would also be the older person's advocate and a social contact; and perhaps it could be a reimbursable medical cost within home services. A 10-15 minute ride can be so much more than getting from point A to B. This would be especially valuable for persons with dementia.

Bill Caplin expressed financial concern from the ASAP lens, which does a lot of work for very low income and frail elders. \$15-17 is nothing to many members of the Council, but to those folks it may seem "impossible."

Roseann DiStefano suggested a family fund (debit card model) with a third payer, which would be especially beneficial for remote caregivers. This would take financial considerations off the older adult's shoulders.

Kate Fichter questioned which needs these *private* companies will be able to fill, since they aren't care providers. Paratransit service is required by federal law, and THE RIDE is not available to people simply because they are older; there are stringent disability constraints.

Steve Kaufman asked Tom Cahir for anecdotal reflection on what ride sharing can actually do in Cape Cod.

Tom Cahir said Cape Cod RTA made an effort to bring all the transportation resources together to improve efficiency (ex: to make sure a bus isn't leaving 5 minutes before a ferry arrives). They also created the 15 week Cape-Flyer train from Boston. Tom said Uber and Lyft have been great partners; Cape Cod RTA has appreciated collaborating with them.

Secretary Bonner thanked the panelists and asked to go around the room and hear thoughts from Council members about issues presented today and how to proceed into the last 2017 Council meeting in December.

Brian O'Grady suggested a more pointed discussion on how to proceed with the themes that have been discussed throughout all the meetings.

Laura Iglesias Lino suggested that the Council look at reliable transportation for providers.

Nora Moreno Cargie noted the Council has a framework but that they aren't going to be able to solve everything. The framework is community. Transportation, affordable housing, etc. and what works in the Berkshires is different than what works in Boston. We must honor what is happening in communities and be willing to pilot new initiatives, with an emphasis on leveraging work within existing infrastructures.

Amy Schectman said the biggest opportunity is to highlight the wisdom of generations. Massachusetts is 49th of 50 in economic security. Battling ageism, bringing information on system gaps, density of development, folks who are modest vs low income have different needs, is it an information gap vs. an actual gap. Housing is the biggest cause of elder poverty.

Bill Caplin highlighted isolation, economic security, and transportation—noting that extremely frail and low-income elders need to be considered and need a lot of help. Bill expressed concerns about technology, which is not always available to frail and low income populations.

Secretary Acosta emphasized that transportation comes up frequently. She loves the idea of technology, but is concerned that many elderly folks aren't using it. The Council could work on a way to disseminate information. From the job/workforce perspective—how are employers designing jobs today? What is being done to accommodate older adults? How to accommodate for both older adults and younger families? The Federal Reserve is interested in studying job design.

Mayor Kevin J. Dumas said he learned a lot from the caregiving perspective and transportation presenters; he highlighted differences from different parts of the state, and the need for specialization in programs and services for individual communities.

Betsy Hampton liked the “information hub” idea, a collection of information centers—with a deep dive into communities. She noted isolation isn't just a problem for older adults but for caregivers as well.

Beth Dugan suggested lifelong driver training, called attention to a medical reporting system to filter out medically unfit drivers.

Steve Kaufman stated that over the last several months, the Council has learned a lot. In thinking about how to move to action items, having 2-3 pilot programs to implement some of these ideas would build infrastructure in communities to help them achieve some of the goals that we've heard about.

Kate Fichter said that, although inadequate, there are several transportation and mobility services, and education is crucial. Solutions from the community level function on the micro level; how can the State make this work at the macro level?

Joe Coughlin also suggested getting information in the hands of the caregiver.

Co-Chair Eileen Connors thanked everyone for coming, and reminded the Council that they can't solve all these problems with the same paintbrush—the issues are nuanced.

The meeting adjourned at 5:06 pm.

The next meeting is scheduled for Monday, December 4th from 2:00 to 4:00 pm – the McCormack Building – One Ashburton Place 21st Floor Conference Rooms 1 & 2 Boston, MA 02108.

Brief Summary of Topics Discussed by Council Members:

- Caregiver isolation and invisibility
- High cost of caregiving
- Lack of caregiver resources/support
- Power of micro level community improvements
- Momentary transportation (transportation on demand)/ Joe Coughlin's “ice cream cone” test
- Population density
- “Wraparound” services
- Technology
- Family driver/payer network

- **Community-specific approaches**
- **Economic insecurity**
- **Workforce/employer involvement**