

Long Term Care Planning Project Meeting 3

Notes – Family Caregiver Support
July 9, 2019

The third meeting of the LTCPP was held on July 9, 2019 and focused on Family Caregiver Support. The meeting included presentations from the staff of the New York State Paid Family Leave program, AARP, and the New York State Office for the Aging (NYSOFA). Following the presentation, participants were asked to discuss a series of questions. At the conclusion of the meeting, participants were offered the opportunity to make a public statement.

Included below are the summaries of the presentations, questions and answers following the presentations, and a summary of the responses for each discussion question.

The presentations are posted on the Department of Health website.
https://www.health.ny.gov/facilities/long_term_care/planning_project/

Presentations

New York State Paid Family Leave (PFL)

Questions and Answers

Q: Do all agencies have to provide Paid Family Leave and is there a minimum number of employees an agency must employ?

A: Almost all private employers are required to offer Paid Family Leave. However, there are certain employers, including public employers, who are not required to offer it unless they opt in.

Q: Why are siblings excluded from the definition of family members?

A: Siblings were not included in the original law.

AARP – Family Caregiving Trends and Innovations

Questions and Answers

Q: Have you seen an effort to create a certification for employers to become age-friendly?

A: There is an opportunity to work more with employers to define an employer age-friendly concept. This is an opportunity for states to present this idea and define what it means. Massachusetts has done some work around the concept of having employers offer employees support and education on Long Term Services and Supports resources.

Q: Is AARP looking at pre and post experience of the CARES program?

A: Yes, there are metrics being continuously tracked.

Q: Where is AARP on culturally competent education for caregivers?

A: It is an important focus of our work and there is more work to be done. Caregiving is so diverse and needs to be culturally appropriate to be effective.

- Q: Do you see AARP taking a step into the direct care workforce to apply your research and information into practice?
- A: We are consumer and advocate focused and would not actively carry out programs in the professional sector. We leverage networking and knowledge to advocate for others to do this to increase adoption and support.

Discussion Questions for Participants

Participants were provided with a list of discussion questions and were asked to discuss them with members at their table. Included below are the responses from those questions.

Question 1: *What specific non-monetary actions can New York take to better support family caregivers?*

- Integrate caregiver information into additional places such as chronic disease grants
- Increase utilization the Medicare Care Plan
- Embed respite programs within the YMCA
- Require dementia screenings during annual exams
- Educate physicians about asking patients who the caregiver is and ensuring that every patient is asked if they are a caregiver
- Require health plans to mandate physicians to collect data on whether a patient is a caregiver
- Better connect community-based services and health care
- Include caregiver comments to hospitals, nursing homes, and doctors in the patient record and medical notes
- Require the hospital discharge system to inform caregivers about respite services and link them to such services
- Encourage more data sharing for benefits across agencies
- Look more closely at language and program names to see if they speak to the caregiver
- Put the family caregiver in the care plan
- Establish policies that align with caregiving in providing complete care needs for patient/family
- Create a virtual platform where all service providers and caregivers can collaborate
- Develop a mobile care plan that includes caregivers and moves with patient to all service providers
- Develop a NYS vision, mission, and values that shape the NYS approach to provision of family caregiver support. We do the “what” well but could do better on shaping the “how.”

Question 2: *What specific actions can New York take to better support family caregivers that will have a fiscal impact on the State Budget?*

- Create drop-in programs for caregivers utilizing university systems and faith agencies
- Loan forgiveness and/or credit bearing service for aide work and respite roles
- Invest in the development of infrastructure for service areas for delivery of Home and Community-Based Services (HCBS) and Long Term Support Services (LTSS), including transportation improvements for patients and caregivers and shorter commutes and more reliable transport options for low wage LTSS workers
- Recognize sibling relationship for respite care and in paid family leave

- Regulate Consumer Directed Personal Assistance Program (CDPAP) Fiscal Intermediaries (FI) to have routine audits to mitigate overutilization
- Routinely collect outcome measures from home-based services
- Increase education to families, including about Paid Family Leave
- Increase education and training for counties and hospital staff
- Develop programs that supplement caregiver's income, similar to PFL, but could fill in gap of percentage not covered by PFL
- Universal Long Term Care (LTC) insurance or make LTC insurance more affordable
- Invest in development of the workforce of formal caregivers
- Increase pay and benefits for home health aides
- Require that Managed Long Term Care Plans (MLTCP) provide respite benefit
- Work with Medicare Managed Care Organizations (MCOs) to expand respite through their flexibility for community-based care provided under new federal rules
- Allow tax credits for caregiver supports
- Allow Assisted Living Centers to provide respite
- Expand programs that pay family caregivers to provide care

Question 3: *What could we do to improve or enhance Lifespan Respite in New York State?*

- Generate more awareness and have better State coordination of information
- Increase availability of respite in rural communities
- Ensure that respite is all inclusive, including clients with behavior or memory deficits
- Increase outreach and education to communities
- Expand grant programs
- Work with local facilities to expand respite services
- Open access to remove insurances barriers and improve coverage for respite
- Increase funding for respite to reduce burden on family caregivers

Question 4: *What new services or models are needed to overcome obstacles and/or build in strengths?*

- Expand PFL to support the health and well-being of caregivers, as well as the person they are caring for
- Engage public and private colleges to provide credits for students who provide volunteer respite services
- Include respite services as a core benefit of MLTCP
- Managed Care or commercial payors create a pilot respite program
- Increase funding for volunteer/respite management organizations
- Create an equivalent of a "Good Housekeeping Seal of Approval" for services

Question 5: *What changes in programs, policies and practices are needed to increase access to respite?*

- Increase access to medical, social day care, and transportation services
- Utilize Assisted Living Programs (ALP) for respite services
- Care coordination for non-Medicaid clients and caregivers through a volunteer respite manager
- Create a program with payors to fund respite services
- Replicate the Alzheimer's Association respite model

- Develop a uniform approach of supporting respite programs across the State
- Provide technology assistance with well check calls/visits from police and EMS workers to allow caregivers to make sure recipient is safe
- Provide additional training for family caregivers and paid caregivers
- Add benefits or incentives for a family member or friend to step in to provide care, for example college credits
- Create incentives for employers to support their employees in taking time to provide the care their families need, for example six hour work day versus an eight hour work day, tax incentives for employer
- Explore creating a need-based/sliding fee scale for respite services for those not covered by insurance
- Create a volunteer blog or website that shares ideas of activities volunteers have done with care receiver to encourage committed, caring, and creative volunteers
- Create transportation vouchers for respite volunteers
- Work with colleges that train health care professionals to develop credit bearing activities that involve respite and other hands-on experience with those in need of care

Question 6: *What are the most effective strategies to identify and connect caregivers to services given that most caregivers do not self-identify as such?*

- Take away term” caregiver” or broaden the term
- Help employees identify as a caregiver
- Develop generic Did You Know e-mails – are you doing “x, y, z? - then you may be a caregiver.” These could come from AARP, EAP programs, etc.
- Have caregiver information available when people log into patient portals
- Change the language, for example instead of “Does your mom need help?” use “Do you need help caring for your mom?”
- Schedule focus groups to determine language
- Keep the NY Connects database constantly updated and share information regarding NY Connects
- Work with health care providers and providers of services that caregivers seek to ensure the providers understand that caregivers are on the same state of change continuum as someone contemplating a behavior change, understand that not everyone has strong family support and a role shift within a family take time, family caregiving may not be the biggest stressor in a caregivers current situation, and the family caregiver with the care receiver may not always be the one with authority to make decisions on behalf of the care receiver.

Question 7: *How could employers be helpful in providing information and assistance to working caregivers?*

- Better communication in linking resources and organizations that exist in the community
- Lunch and learns given by a professional organization
- Employer’s Human Resources (HR) departments give seminars to their employees about Paid Family Leave
- Every employer should educate the staff regarding local resources through a resource list being provided upon hire or other methods

- State mandate employers to list and educate employees regarding available resources
- New employee orientation packet
- EAP training
- Supervisor training
- Flexibility in approval request for time
- Electronic payroll sites, benefit sites have information and embed more in HR notifications
- Bring health fairs to the work place
- Utilize their own intranet to promote services
- Easy access to PFL – make sure employees know it's available and assist with applying
- Find out how many caregivers there are among employers
- Increase flextime and ability to work remotely
- Have employers participate in caregiver simulation to understand time commitments
- Ask caregiver which benefits or perks they would use or appreciate
- Be conscious of planning employer sponsored events to accommodate caregiving needs