



NEW YORK
STATE OF
OPPORTUNITY

Office for
the Aging



**2018 Regional Caregiver
Forums and Listening Sessions**
Highlights and Summary



A Message from the Director

The tremendous role that family, friends, and neighbors play in assisting older adults and individuals of all ages with varying abilities with tasks to help them maintain their independence cannot be overstated. It is difficult to imagine health care or long-term care reform without considering the central role caregivers play in carrying out discharge plans or in helping people avoid more costly care. Caring for someone else can bring joy and fulfillment but can also be stressful and exhausting. New York State recognizes the value of caregivers and has worked to address caregiver needs and to build capacity in communities across the state. Under Governor Andrew Cuomo's leadership, investments in caregiving services have been unprecedented. Governor Cuomo's vision to advance a Health

Across All Policies approach and imbedding healthy aging into all aspects of government work supports the role of caregivers. The Governor's 2018 State of the State proposal to launch a Long Term Care Planning Project (LTCPP) to map out a 10-year plan to meet the emerging needs of New York's aging population will further address caregiver issues, and Executive Order #190, which incorporates age-friendly concepts and healthy aging into government planning and procurement will have a positive impact on caregivers of all ages and populations.

I would like to thank the broad array of partners in caregiving across New York State for their support and active participation in the 2018 Regional Caregiver Forums. Caregiver training and listening forums are a great way to get real time information on what is successful, where gaps exist, and what we need to consider moving forward to support these amazing people. The findings collected at these events will help inform NYSOFA's efforts to advance Governor Cuomo's continued commitment to ensuring that older adults and caregivers have access to the vital long-term care services and supports they need to remain healthy and engaged in their communities. There are approximately 4.1 million people providing direct, hands on care in any given year. And it is well documented that over 80% of long-term care is provided informally, so it is critical that as a state we continue to explore more effective ways to support and assist family caregivers. This summary will be shared with members of the Governor's administration involved in the Long Term Care Planning Project and help advance his Health Across All Policies agenda that seeks to make New York the healthiest state in the nation and an even greater place for all New Yorkers to grow up, work, and grow older.

Specifically, I want to recognize our key partners including the Association on Aging in New York State (AgingNY), Kelli Owens, Director of Women's Affairs, Office of Governor Andrew M. Cuomo, the members of the New York State Caregiving and Respite Coalition (NYSCRC), the New York State Kinship Navigator, and all those who gave of their time to share their experience and recommendations. In addition, I would like to acknowledge Jennifer Rosenbaum, Assistant Director of the Division of Policy, Planning, Program, and Outcomes, Deana Prest, Aging Services Program Analyst 3, and all the staff at the New York State Office for the Aging who were involved in organizing the forums and developing the findings highlighted in this summary. In addition, I would like to thank Doris Green, Director of NYSCRC, who was a key partner in making these forums a great success.

A handwritten signature in black ink, appearing to read 'Greg Olsen', written in a cursive style.

Greg Olsen
Director, New York State Office for the Aging



2018 REGIONAL CAREGIVER FORUMS AND LISTENING SESSIONS Highlights and Summary

Background

New York State's 4.1 million unpaid caregivers deliver the bulk of long-term services and supports in the state. According to AARP, the economic value of this care exceeds \$32 billion if paid for at the market rate.

Caregivers include any relative, partner, friend or neighbor who has a significant personal relationship with and provides a broad range of assistance for a loved one. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care. The important role that caregivers play in helping support the autonomy of individuals is clearly understood. New York State is working to improve the assistance provided to individuals who assume this role to help advance Governor Andrew M. Cuomo's efforts in making New York age-friendly; assisting people to live independently; and helping to further efforts that comply with the Olmstead Supreme Court decision. As a result of these developments, addressing the needs of

caregivers is now considered a key element of efforts underway to reform our long-term care system.

There are a variety of programs supported by New York State that assist caregivers. Many services offered through the New York State Office for the Aging's (NYSOFA) 59 locally-based area agencies on aging and network of almost 1,200 community-based service providers each day seek to achieve this objective. Over \$100 million of NYSOFA's resources support caregivers or provide support to the loved ones of caregivers that can reduce their workload. NYSOFA also invests significant resources to assist caregivers through NY Connects, transportation services, older adult nutrition programs, and health and wellness initiatives. Additionally, New York supports caregivers through a variety of programs and partnerships funded from various sources administered by the Department of Health and its extensive provider networks, and in collaboration with the New York Coalition of Alzheimer's Association chapters.

The 2018 caregiver forums were highlighted through the New York State Caregiving and Respite Coalition (NYSCRC), which is tasked with developing coordinated systems of accessible community-based respite care services to family caregivers. This effort is funded by a federal grant from the Administration on Community Living to NYSOFA through the Lifespan Respite Act. Also, the Association on Aging in New York (AgingNY) supported this work and continues to make training available to its members designed to improve their ability to serve caregivers and increase overall access to services.

The importance of caregiving and the substantial investments being made in supporting individuals in this role have enhanced the visibility of this issue, which will be a topic discussed at the state's Long Term Care Planning Project (LTCPP) meetings. This project, which was announced in the Governor's 2018 State of the State address, is anticipated to yield many recommendations that will assist caregivers. This work is being undertaken with an understanding of the rapidly changing demographics and changing needs of New York's growing aging population. The LTCPP will analyze, evaluate, and identify the existing service gaps in the long-term care system; determine the most cost-effective evidence-based interventions; and prepare a strategic plan to meet the emerging needs of New York's aging population over the next decade. Data collected at the 2018 Caregiver Forums will be shared at events planned as part of the project. The findings of the forums have been organized around the challenges caregivers face each day to address the needs of a loved one, which will help inform discussions underway by policymakers brought together by the Governor on how best to improve the long-term care services and supports system.

2018 Regional Caregiver Forums

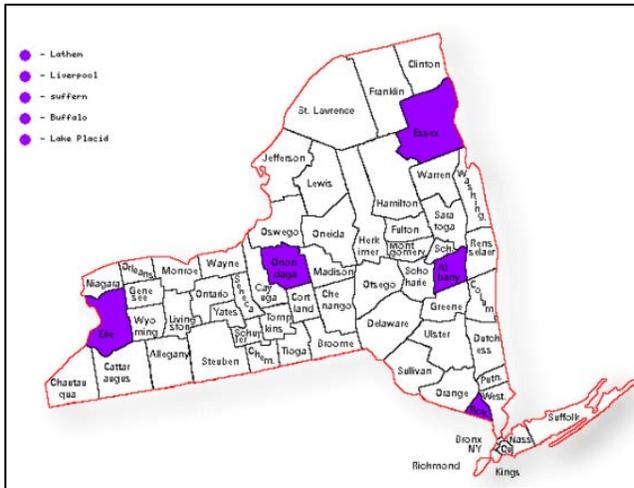
Section 206 of the NYS Elder Law, Article II, Title I established the Caregiver Assistance Program within the New York State Office for the Aging (NYSOFA). Under this program, NYSOFA is authorized to establish training and assistance programs for caregivers of people who are frail or who have disabilities. As part of this effort, NYSOFA undertakes, in partnership with others, annual Regional Caregiver Forums.

In spring 2018, NYSOFA, AgingNY, NYSCRC, and the New York State Kinship Navigator partnered to facilitate five regional caregiver forums.

The purpose of the regional forums was to engage the general public, staff who administer and/or provide caregiving and NY Connects services, and those in the New York State KinCare Coalition to better understand what current caregiver and respite supports and services are available statewide. These events also provided a venue to discuss strategies about ways services could be expanded and enhanced through innovative ideas and strong partnerships across age and disability groups.

Staff who oversee and provide caregiving and/or NY Connects services, as well as those in the KinCare Coalition were encouraged to attend to better understand what current caregiver and respite supports and services exist and to discuss ways they can offer more through innovative ideas and strong partnerships. NY Connects is a locally-based system designed to provide screening, information, application assistance, connection to services, and person center counseling. It is designed to assist individuals and caregivers needing long-term services and supports across service systems regardless of age, disability, health condition or income. NY Connects also assists professionals seeking information, assistance, and services on behalf of those they are helping. The KinCare Coalition provides a voice In New York State to an estimated 179,000 caregivers, 131,000 of whom are grandparents.





The 2018 Regional Caregiver Forums and Listening Sessions were held in the following locations:

- Latham – April 30
- Liverpool – May 3
- Buffalo – May 8
- Suffern – May 15
- Lake Placid – May 23

These regions were chosen to offer attendance opportunities across the state with the aim of including urban, suburban, and rural communities in discussions about caregiving and respite.

The intended audience for the forums included AAA leadership, staff, and subcontractor staff involved in assisting caregivers (such as caregiver program coordinators), staff providing NY Connects services, KinCare Coalition members, community-based organizations, caregivers, NY Connects staff from Independent Living Centers under contract with NYSOFA, and local caregiver coalition members, among others. The forums helped strengthen the network of partners and provided opportunities for sharing issues, needs, and ideas on behalf of caregivers that professionals serve. The forums were divided into two parts:

Part I: Morning Training Review and Discussion: Learning Objectives

The morning session offered an in-depth review of caregiver training materials and discussion about resources to support caregiving and respite service needs in the aging network. Presentations on NY Connects and its services, as well as the New York State Kinship Navigator and its programs and services, were provided for caregivers who care for individuals across the age and disability spectrum. Presenters included the Lifespan Respite Care Program director, NYSCRC director, and the regional Kinship Navigator staff.



The learning objectives for the morning included:

- Introducing and understanding NYSCRC’s mission, and how it interconnects with NYSOFA, AAAs, NY Connects, and the KinCare Coalition, to support all people engaged in caregiving.
- Enhancing the understanding of NYSCRC’s role in building respite capacity and caregiver supports across New York State, and how participants can get involved.
- Learning about what services are available, how to access them, and when to use the new Statewide Caregiving and Respite Virtual Resource Center (VRC) housed at NYSCRC.
- Expanding referral sources and engaging partners in conversations on caregiver needs and resources across the lifespan.
- Becoming familiar with Lifespan Respite sustainability and ways participants could support it.
- Increasing the understanding of the NY Connects system and its role in streamlining access to respite and other caregiver supports and services, including the NY Connects web-based resource directory.
- Determining strategies for developing innovative programs to serve caregivers using person-centered approaches through a variety of supports and services.

As part of the morning sessions, attendees participated in a structured brainstorming exercise to respond to the question, “How might organizations that provide or oversee caregiver/respite support services be brought together locally, regionally, and/or statewide to work together to increase access to respite options?” The goal of this exercise was to assure that recommendations on better ways to connect were discussed with providers and administrators of caregiver and respite services. Participants were instructed to document their ideas, share their responses and ideas with others, and rank the responses.

Part II: Afternoon Listening Sessions

The afternoon session was facilitated by Kelli Owens, Director of Women’s Affairs in the Governor’s office. The afternoon listening sessions were open to family caregivers. Participants were invited to have small group discussions and reflect on how caregiving brings them joy, or in their role as professionals, how serving caregivers brings them joy. This approach was used because caregivers are often invited to share the stresses of caregiving, but rarely given the opportunity to reflect on the positive aspects of their caregiving role. Following this opening, Director Owens shared her personal caregiving story and facilitated the listening sessions, which aimed to engage participants to identify and discuss effective strategies to address caregiver challenges and determine ways to reduce barriers and address gaps.



Findings and Results

The forums had a total of 160 participants. Participant feedback forms indicated a high percentage of the professional participants were either informal caregivers currently or had been an informal caregiver outside their professional role. Participants with caregiving experience were invited to share their stories and offer recommendations on ways to address gaps and reduce barriers to accessing services and supports for New York State caregivers.

Morning Brainstorming

Following the morning training on caregiver and respite services and supports, participants engaged in a brainstorming exercise to respond to the following question: “How might

organizations that provide or oversee caregiver/respite support services be brought together locally, regionally, and/or statewide to work together to increase access to respite options?”

The process to address the question employed a facilitation technique (called 25/10 crowd sourcing) that can help a large group generate and sort ideas for action in 30 minutes or less. While it is fun and fast, it is also a serious and valid way to generate an uncensored set of ideas and then tap the wisdom of the whole group to identify the top 10.

More than 150 ideas were generated by participants, spanning categories including:

- Additional opportunities to network and share information;
- Expanding use of social media;
- Additional resources to reach more caregivers; and
- Expanding the use of technology.

Afternoon Listening Sessions

The afternoon listening sessions sought to identify and discuss effective strategies to address caregiver challenges and determine ways to reduce barriers and address gaps. Forty (40) general topics surrounding caregiver needs were identified. The topics were grouped into 19 categories. Five of those topics were discussed at four or more of the forums and had higher frequencies of being discussed in the listening sessions than any of the other 14:

Categories:	*Frequency	**Forum Count
1. Funding needs	31	5
2. Need for discharge planning (with caregivers)	11	5
3. Difficulties with respite	9	4
4. Increase public education/awareness	11	4
5. Need to attend to caregiver health	13	4
6. Lack of caregiver self-identification	3	3
7. Need for health insurance counseling	5	3
8. Funding options	3	2
9. Increase access to transportation	4	2
10. Increase oversight of MLTC	2	2
11. Telehealth	2	2
12. Assist in identifying supports	4	1
13. Issues with data sharing	1	1
14. Issues with means testing for long-term care	1	1
15. Lack of informal supports	2	1
16. Need for personalized case management for caregivers	2	1
17. Restrictive financial eligibility criteria	1	1
18. Services need to attend to caregiver schedules	1	1
19. Utilize EMS personnel	1	1

* *Frequency: How many times did the topic come up across the five forums*

** *Forum count: At how many forums was the topic discussed*

In addition to participating in the listening session, participants were invited to submit a participant form at the end of the forum.

The form was developed to provide the opportunity for all participants to provide their input and feedback. Participants were asked to review a list of 14 recommendations and could add their own recommendations under “Other.” They were asked to select five in the list that they felt were most important. The 14 recommendations are noted in the chart, below, with the statewide aggregate total number of times the recommendation was selected in the second column, and the percent of the total times it was recommended reflected in the third column.

The five recommendations with the highest number and percent of total responses are in bold (Recommendations 1,2,4,6, and 7).

Feedback Form: State Aggregate Totals

Recommendation	# of Selections	% of Total
1. Enhance access to information about services and supports that help caregivers remain in their role.	53	10%
2. Increase access to in-home services and supports.	89	16%
3. Increase access to technological solutions to help caregivers in their role.	19	3%
4. Develop strategies that help caregivers advocate within the health care system on behalf of their family member/ or friend.	45	8%
5. Make available information to assist caregivers in addressing their nutritional needs and of those for who they are caring.	3	1%
6. Improve availability of respite to provide caregivers with breaks to prevent burnout.	86	16%
7. Enhance strategies for providing access to home modifications to help an older adult with functional impairments to remain safely in their homes with the support of a caregiver.	55	10%
8. Expand access to training to assist caregivers in their roles.	29	5%
9. Have training available that assist caregivers specifically in managing difficult behaviors.	34	6%
10. Develop strategies to help caregivers deal with social isolation/ loneliness they might experience while they focus on their roles.	38	7%
11. Assistance in addressing alcohol and substance abuse issues experienced by caregivers.	8	1%
12. Provide guidance to address/ manage the stresses that affect the mental health of caregivers.	37	7%
13. Help manage the stresses of multi-generational caregiving on the extended family.	18	3%
14. Provide information about the impact of caregiving on overall health and wellness.	25	5%
15. Other	13	2%
Total	552	100%

Summary

After comparing the information gathered from the forums, the topics identified as most valuable included: networking and information sharing, public education/awareness, caregiver advocates in the health care system, and increased funding for caregiver support programs.

Participants noted networking and information sharing as both a strength of the forums and an area that they would like to see expanded at future events sponsored by the Coalition. Participants documented ideas such as regional webinars and networking events as ways of facilitating this information sharing.

Increased public education/awareness was a two-pronged topic. The forums revealed that professionals need to be more aware of the needs of caregivers and more attentive to caregiver preferences. This topic also covered the need for information on services to be more widely distributed in communities, as many caregivers do not know what supports are available to them.

The identified area of assisting caregivers in advocating on the part of any relative, partner, friend or neighbor involved in the health care system covers areas such as the need for discharge planning and the need for programs that assist caregivers in navigating the health care and long-term services and supports systems.

Increasing funding for caregiver programs involved respite programs and caregiver mental health programs, in-home services, and home modification programs for care receivers to alleviate some of the strain on caregivers and support caregivers in their role.

Addendums - see <http://bit.ly/OFARegCare>

2018 Caregiver Forums and Listening Sessions – Data

New York State Caregiving and Respite Coalition (NYSCRC)

Caregiving and Respite Across the Lifespan: Linkages and Partnerships 2018

Kelli Owens, Director of Women's Affairs, Office of Governor Andrew M. Cuomo, personal caregiving story

Notes



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