

REPORT: CAREGIVERS IN CRISIS

WHY NEW YORK MUST ACT

November 2013



EXECUTIVE SUMMARY

At any given time during the year, over four million family caregivers in New York State are providing unpaid care for a loved one, contributing an estimated 2.68 billion hours annually at an estimated worth of \$32 billion.

Over the summer of 2013, AARP New York, the Council of Senior Centers and Services of New York City, Inc., and the NYS Caregiving and Respite Coalition, along with several organizations concerned with the wellbeing of frail New Yorkers, convened a series of 12 listening sessions across New York in Albany, Brooklyn, Buffalo, Elmira, Glens Falls, Manhattan, Oakdale, Rochester, and Syracuse to hear directly from caregivers and service providers.

The purpose was to learn about the challenges facing caregivers (family, friends, and neighbors) and to find ways to help family caregivers working to keep older adults living independently and safely in their homes and communities and out of expensive and mostly taxpayer-funded institutional settings. Throughout these listening sessions, caregivers clearly articulated what type of services and system supports they need.

Over 900 people, all with direct experience in caregiving, attended. In addition, AARP received nearly 500 responses to an online survey from caregivers and service providers expressing their needs and possible solutions to their issues. (Please see Appendix A for a text version of the survey.)

New York's caregivers need help. A 2011 national report by AARP's Public Policy Institute, the Commonwealth Fund, and the SCAN Foundation found New York ranked 48th out of 50 states with regard to support for its family caregivers, and those caregivers attending the New York listening sessions this year supported that conclusion.

According to the New York State Office for the Aging (SOFA), the typical caregiver in the New York aging services system is a 64-year-old female who has either high school or some college education and spends more than 40 hours a week providing care to her mother. Almost 25% of those providing care are aged 75 or older.

The majority of the care receivers (85%) are aged 75 or older and average 82.3 years of age. Of those with at least one health problem, Alzheimer's or another dementia was the most prevalent condition. SOFA estimates that unpaid caregivers provide the majority of all long-term care services to older adults and individuals with disabilities. According to SOFA in *Sustaining Informal Caregivers New York State Caregiver Support Programs Participants Survey (2009)*, many caregivers reported that without the services of state programs supporting family caregivers, they would be forced to place their loved ones in institutional settings like nursing homes that are funded largely by taxpayers through the Medicaid program.

Employers are also adversely affected by the strains on caregivers. A 2006 MetLife study found businesses lose as much as \$33.6 billion annually in worker productivity because of employees' caregiving obligations.

The need to help caregivers will only increase in the coming years as the baby-boom generation ages and the number of younger people proportionately decreases. Already, the number of caregivers in New York has grown to 32% from 25% in the 1990s. And a recent AARP report found that while there were

6.6 potential caregivers aged 45 to 64 for every person in the high-risk years of 80+ in New York in 2010, there will be only 4.8 in 2030 and 3.5 in 2050.

AARP New York, the Council of Senior Centers and Services of New York City, Inc., and the New York State Caregiving and Respite Coalition strongly believe there is a great opportunity for the Governor and the New York State Legislature to help millions of New Yorkers with their caregiving needs, keep older adults living in the community, maintain worker productivity, and potentially save scarce tax dollars being spent on expensive institutional care.

This paper highlights these needs and provides a series of recommendations for New York State's policy makers to address. AARP New York, the Council of Senior Centers and Services of New York City, Inc., and the New York State Caregiving and Respite Coalition stand ready to work with the Governor and the Legislature to develop and implement sound policies to help those caregivers in need.

POLICY RECOMMENDATIONS

The recommendations in this report are based on the testimonies of caregivers from the 12 listening sessions and the online surveys. The following is a short summary of policy recommendations to support caregivers in keeping loved ones at home rather than in institutional settings. Each of these recommendations is explained in further detail within this report and is accompanied by recommended action steps.

1. Establish a Community Care Navigator (CC Navigator) program by reinvigorating and enhancing the existing NY Connects program. CC Navigator will help caregivers and all New Yorkers develop a personal roadmap to direct them to the information, services, and supports they need. This plan would include aggressive outreach and public education campaigns to bring awareness of the new program.
2. Provide adequate funding to SOFA for non-Medicaid-funded caregiver assistance programs that will help caregivers keep seniors living at home, thereby reducing Medicaid expenditures on institutional care.
3. Provide training and skill-building for caregivers to help them cope with the various medical tasks and needs their elderly loved ones have. If the loved one is in a hospital or other rehabilitation facility, the training and skill-building should occur prior to discharge. All facilities should record the name of the family caregiver(s) upon admission and contact the person(s) prior to discharge to another facility or to home.
4. Review paid and unpaid family leave policies to assist working caregivers and support businesses. A 2006 MetLife study found companies lose as much as \$33.6 billion annually in worker productivity because of employees' caregiving obligations. Examine successful approaches implemented in other states and determine their feasibility for New York State. Support workplace policies that prohibit discriminatory employment practices against working caregivers.

5. Ensure access to competent legal assistance and pass legislation to protect vulnerable people from fraud and financial exploitation.
6. Promote and increase a diverse range of affordable housing options that allow older adults to age in place and be part of an active community that embodies elements of walkability, universal and inclusive housing design features, and accessible transportation.
7. Support volunteer models that build social networks using both peer-to-peer and intergenerational approaches.
8. Promote changes in the work environment that encourage direct-care staff recruitment and retention.

BACKGROUND: THE CAREGIVER IN NEW YORK STATE

For the purposes of this report, a family caregiver refers to any unpaid relative, partner, friend, or neighbor who has a significant relationship with and who provides a range of assistance for an older adult or an adult with a chronic or disabling condition(s). From research conducted by AARP in *Valuing the Invaluable: 2011 Update - The Growing Contributions and Costs of Family Caregiving*, which arrived at estimates of the economic value provided by family caregivers, over four million such family caregivers in New York provide an estimated 2.68 billion hours of unpaid care per year at an estimated worth of \$32 billion.

According to the New York State Office for the Aging (SOFA) in *Sustaining Informal Caregivers New York State Caregiver Support Programs Participants Survey (2009)*, the person most likely to be providing care to an older person is a daughter (48%), followed by a wife (23%), a husband (10%), and a son (10%).

The average U.S. caregiver is a 49-year-old woman who works outside the home and spends nearly 20 hours per week providing unpaid care to her mother for nearly five years. More than eight in 10 are caring for a relative or friend aged 50 or older. The typical caregiver in the New York aging services system is a 64-year-old female who has either high school or some college education and spends more than 40 hours a week providing care to her mother. Almost 25% of those providing care are aged 75 or older.

In New York State, the majority of the care receivers (85%) are aged 75 or older and average 82.3 years of age. Of those with at least one health problem, Alzheimer's or another dementia was the most prevalent condition.

The number of New York families and neighbors providing help to frail individuals has been growing. The current percentage of New Yorkers providing such support is now 32%, up from around 25% throughout the 1990s.

According to SOFA, unpaid caregivers provide the majority of all long-term care services to older adults and individuals with disabilities. SOFA estimates that without the support of these unpaid caregivers, over 50% of older residents would likely be placed in institutional settings, like nursing homes, that are funded largely by taxpayers through the Medicaid program. Research studies and reports, such as AARP's

Valuing the Invaluable: 2011 Update - The Growing Contributions and Costs of Family Caregiving, clearly demonstrate that family support is a key factor in determining an older person's ability to remain in his or her home and community and out of institutional care settings such as nursing homes.

WHAT NEW YORK MUST DO TO SUPPORT FAMILY CAREGIVERS

New York State's lack of commitment to caregivers comes at the wrong time when current demographic trends are taken into account. New York State is fourth in the nation in the number of adults aged 60 and over with about 3.7 million (1.3 million in New York City). The 60+ group increased by 15% statewide between 2000 and 2010, and this figure will only rise as the post-war boomer generation continues to age. Furthermore, across the state, while the 60+ age group is increasing rapidly, the under-60 population is shrinking in many counties.

That shift will decrease the number of potential caregivers aged 45 to 64 for every person in the high-risk years of 80+ in New York from 6.6 in 2010 to 4.8 in 2030 and 3.5 in 2050, according to a recent report from the AARP Public Policy Institute, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers*.

SOFA and the network of county Area Agencies on Aging (AAA) provide services to caregivers through several community-based programs. However, because of insufficient funding, these agencies are at a great disadvantage in assisting all caregivers who need help.

New York State policy on long-term care since Andrew Cuomo became governor in 2011 has been largely focused on slowing the growth of Medicaid. The Medicaid Redesign Team (MRT) process reformed New York's Medicaid program through the institution of a managed care model for the delivery of Medicaid services, including long-term care. However, little discussion has occurred on how to slow the growth of Medicaid by investing in nonmedical community-based programs, particularly those assisting caregivers. This is clear when examining the SOFA budget.

A recent review by AARP of the current SOFA budget reveals that less than \$3 million in state funds are specifically appropriated for programs primarily focused on assisting caregivers including respite and social-model adult day care as well as transportation services. The budget does provide some caregiver support through the Expanded In-Home Services for the Elderly Program (EISEP) and Community Services for the Elderly (CSE) (see Appendix B for more information). But caregivers and professionals in aging services are in full agreement that while these programs are not expressly designed to support caregivers, both programs are underfunded, and EISEP currently has a waiting list for services in many counties.

In 2011, AARP's Public Policy Institute, the Commonwealth Fund and the SCAN Foundation published research findings in *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*, an innovative multidimensional measurement of state-level performance of long-term services and supports systems that provide assistance to older people and adults with disabilities. The scorecard examined four key dimensions of performance: affordability and access, choice of setting and provider, quality of life and quality of care, and support for family caregivers. It assessed each state's performance as a whole and on 25 individual indicators.

This report found that performance varied tremendously across states. New York ranked 48th out of 50 states with regard to support for its family caregivers. Caregivers at the 12 listening sessions reinforced this finding. Their comments clearly reflected frustration and helplessness when they sought assistance to understand and appropriately address the situations they face caring for their elderly loved ones.

As described in the Council of Senior Centers & Services of NYC's *No Time to Wait: The Case for Long-Term Care Reform*, with the state's aging population growing rapidly and the proportional balance between older and younger populations shifting, it is apparent that a coherent strategy is needed to assist caregivers. This should help slow the growth of Medicaid in New York State. A policy that provides older New Yorkers what they need and what their families want—to live independently in their communities—and that saves taxpayers money on expenditures for institutional care is well worth pursuing.

POLICY RECOMMENDATIONS BASED ON CAREGIVER LISTENING SESSIONS

I. Establish a Community Care Navigator (CC Navigator) Program

Caregivers often have limited information about what resources are available, a problem compounded because care frequently commences during a crisis. Caregivers expressed the need for guidance through the confusing options of services. They seek not only information about available services but also help in making critical decisions about their unique situations. Caregivers voiced the need for someone to help navigate the system and identify available services, serve as a consultant in developing a “roadmap” of services and supports, and follow up on their progress. They asked that these services be responsive, flexible, easy to find, and readily available. In some of the listening sessions, participants also expressed their dismay at the lack of coordination and cooperation among providers and state and federal agencies.

New York State has made some advances in enabling older adults and people with disabilities to receive objective information about the long-term care system through the NY Connects program. These efforts grew out of the federal Aging and Disability Resource Centers (ADRC), which aim to help people navigate the long-term care system and receive the services they need. However, many caregiver participants were unaware of the existence of NY Connects and that services might be available for them.

NY Connects, based in county AAAs in collaboration with local Departments of Social Services, has never been fully implemented statewide. It does not operate in the five counties of New York City and in four other counties. Additionally, the information that NY Connects provides is limited to the likelihood of eligibility for services and does not include traditional case management, assessment, or referral.

The Balancing Incentive Program (BIP), authorized under the Affordable Care Act, provides states with additional federal funding to implement structural changes that are believed to best facilitate rebalancing the percentage of individuals in need of long-term supports and services in home- and community-based settings as opposed to institutional settings. New York's application to participate in BIP was approved on March 15, 2013.

Many advocates for aging services across New York State strongly believe that some of the BIP money should be directed not only at helping families gain access to and information about home- and community-based services but also at helping family caregivers navigate the system so that their loved ones can remain at home or in the community.

Recommended Actions:

- **Establish the CC Navigator program** to reinvigorate and enhance NY Connects so that individuals and their caregivers have the information and support needed to understand their options and access services and supports based on their needs and preferences. CC Navigator should include *screening and assessment* of the individual and the person's needs, a thorough *assessment of caregiver needs*, *options counseling*, *assistance in developing a plan of care* that gives priority to the needs and preferences of individuals and caregivers, *case management*, *presumptive eligibility determinations*, and *assistance in making the service connections* that are most responsive to their needs. CC Navigator would maintain the existing NY Connects services but would build upon them and provide additional services using funding, as appropriate, from the NYS BIP. The CC Navigator program would be implemented in every New York State county including the five counties of New York City.
- **Engage in aggressive outreach and public education campaigns** to build awareness of the new CC Navigator through use of traditional print and media as well as social media. As indicated above, caregiver participants at the listening sessions expressed frustration that they were unaware of the NY Connects program.
- **Develop and expand working collaborations between CC Navigator and the Veterans Administration, hospitals, rehabilitation centers, and nursing homes**, which are critical points of entry into the long-term care system. This should include training all admissions and discharge planners about services available in their communities. In addition, links and collaboration between CC Navigator and Alzheimer's resource centers and associations will work to better meet the needs of older adults with Alzheimer's disease and dementia. Improving these collaborations will help to prevent unnecessary readmissions and costly institutionalization.

II. Invest in Caregiver Assistance Programs that are Individualized, Flexible, and Consumer-Centric

A comprehensive 2013 AARP New York survey of registered voters aged 50+ on caregiving and home- and community-based services revealed the majority of respondents supported increased state funding for caregiver services. The survey respondents also believed it is important to have a range of services in their communities. The caregivers at the listening sessions echoed these survey results.

Caregivers are frequently elderly themselves, the typical New York caregiver being 64 years old. The needs of the older adult increase as they age and become increasingly frail, and the gradual decline creates even greater financial and emotional stress for the caregiver, whose own personal needs can also be increasing. Caregivers across the state shared stories about their experiences of providing care all

day, every day. Many indicated they rarely get a break, and, when they do, it is often with only a piecemeal plan. Caregivers become conflicted about whom to care for first, their loved ones or themselves.

Caregivers clearly described problems with the system and recognized the near absence of nonmedical services to give them a break or to advise them on how to care for their elderly loved ones in the home. They are looking for high-quality services that are affordable, especially respite and transportation services. One caregiver expressed it this way: “*We are buying a product for the most important person in our lives.*” Caregivers’ experiences with EISEP were extremely favorable, but they were concerned about the small number of hours provided and the long waiting lists.

An additional concern that arose during the listening sessions was that the costs of these services were unaffordable for those with moderate incomes. One caregiver remarked that her husband is a “sundowner” who stays awake all night and sleeps all day. For her to get some rest, the family privately paid an aide to assist with night care. “*The arrangement forced us to spend one-third of our limited income on aide services, impacting spending on other needs,*” she said. Over and over caregivers gave examples of spending their scarce resources to keep their family members at home.

Caregivers unanimously voiced the need to ensure that long-term care services and supports are individualized, flexible, and consumer-centric. Many caregivers described current programs as rigid, standardized, and unable to meet their unique needs and preferences. One recent demonstration program in New York documented the benefits of consumer-directed approaches for older adults. The Nursing Home Diversion and Modernization Project implemented through the AAA used consumer-directed approaches and found that 81% of high-risk older adults who participated were diverted from nursing home placement, and 83.5% were diverted from Medicaid spend-down (Center for Excellence, 2011).

Recommended Actions:

- **Provide immediate funding** to serve the New Yorkers currently on waiting lists for caregiver assistance programs including respite care, social-model adult day care, and transportation services as well as additional funding for EISEP and the CSE program. The Governor and Legislature should approve additional funding for these ultimately money-saving services in the 2014-15 state budget.
- **Incorporate questions on caregivers’ needs into all community-based and medical assessments** as part of a family-centered approach to services. Caregivers should be involved in care plan development and modifications.
- **Promote and expand opportunities for consumer-directed care** for all long-term care home- and community-based services. This should allow for selecting the type and timing of services, hiring and managing workers, purchasing supplies, making home modifications, and hiring and paying for someone, such as a neighbor, friend, or family member, to provide personal care for older adults of all incomes.

III. Provide Training and Skill-Building for Caregivers

At the listening sessions, caregivers of seriously or chronically ill older adults were particularly concerned about their lack of preparation for the responsibilities of caring for their loved ones as they transitioned from hospitals back to their own residences. Once home and frequently alone with their relatives, caregivers are often overwhelmed when required to give injection, change catheters, or perform other medical tasks.

In hospitals or other medical settings, nurses and aides perform these complicated, skilled tasks. Family members are frustrated at the lack of training, education, and skill-building available to them. For example, one caregiver described not being taught the proper technique to transfer her husband between his wheelchair and the bed, and she expressed concern about hurting both herself and her husband.

In addition, all too often, family members did not receive advance notice that their loved ones were being discharged. Even when notice was provided, they may not have been involved in the development of the discharge plan, or, even if they were, they did not feel adequately prepared, given the magnitude of what to remember and do once their loved one returned home. Multiple caregivers echoed this complaint, emphasizing that caregivers need more preparation during this critical time.

Based on comments, training also needs to go beyond performing medical and skilled tasks. Caregivers expressed the need to know more about Alzheimer's disease, how best to interact with care recipients, and how to address more challenging behaviors, especially as the disease progresses. They asked for information about providing a safe environment when their loved ones wander. Finally, caregivers voiced the need to become better advocates for their relatives, whether they live at home or in a residential facility.

Caregivers described how they have become de facto case managers for their older relatives, making certain that services are available and dependable, organizing and managing aides, and arranging for transportation to medical appointments.

In addition, caregivers stated that professionals in the field of aging need to have a better understanding of their unique needs. When a professional performs an assessment of an older adult, the role, frequency, and availability of the caregiver should be discussed and incorporated into the care plan. This is especially true when an older adult requires hospitalization; family caregivers want and need to be kept informed of all major decisions.

Recommended Actions:

- **Require hospitals and rehabilitation institutions to record the name of the family caregiver(s) upon admission into the facility** and require the institution to contact the family caregiver(s) prior to discharge to another facility or to home.
- **Require a facility to provide live demonstrations** of any medical tasks and training the caregiver requests prior to the time the older adult is discharged. With this training, caregivers can provide competent post-hospital or post-rehabilitation care to their loved ones.

Another positive outcome of providing caregivers with education and training in medical and related tasks is the expectation that it will reduce the number of costly hospital readmissions. The federal Centers for Medicare/Medicaid Services (CMS) estimates that \$17 billion in Medicare funds is spent each year on unnecessary hospital readmissions. Additionally, hospitals desire to avoid the imposition of new readmission penalties under the Affordable Care Act (ACA).

- **Facilitate additional training for caregivers** through a variety of modalities such as webinars and at public libraries, senior centers, and other community settings, under the direction of SOFA. Training should address personal care tasks as well as medical- and nursing-delegated tasks of wound care, medication management, incontinence care, and mobility.

IV. Support Working Caregivers

Caregivers who are employed face many demands and competing commitments. They experience high levels of stress, limited personal time, concern for their own physical and mental health, loss of quality of life, and potential impact on their employment. *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business* found that 60% of caregivers nationwide are employed, and businesses across the nation lose between \$17.1 and \$33.6 billion per year (MetLife, 2006).

Frequently, caregivers at the listening sessions talked about the job of caregiving creating such overwhelming demands they had to leave the workplace. People who decide to devote themselves to full-time caregiving suffer both short- and long-term ramifications, including losing health insurance and retirement security and becoming isolated and losing their social and emotional support networks.

The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents estimated the value of lost wages, pensions, and Social Security due to caregiving responsibilities, which they have termed the “caregiver glass ceiling” (MetLife, 2010). Notably, for women, the total individual amount of lost wages due to leaving the labor force early and/or reduced hours of work because of caregiving responsibilities equals \$142,693. The estimated impact of caregiving on lost Social Security benefits is \$131,351. A conservative estimated impact on pensions is approximately \$50,000. Thus, the total cost impact of caregiving on the individual female caregiver equals \$324,044.

Recommended Actions:

- **Explore both paid and unpaid family leave** approaches implemented in other states and determine the feasibility for New York. One avenue would entail New York expanding job-protected leave policies established through the federal Family and Medical Leave Act (FMLA) of 1993. As of August 2013, as many as 20 states provide some type of leave that is more generous than the FMLA. Most of these state laws increase the number of people who can access the FMLA by altering the eligibility requirements, expanding the range of family caregiving relationships, or increasing the amount of unpaid leave that can be taken.

The analysis should include whether to add paid family leave to the existing Temporary Disability Insurance (TDI) partial wage-replacement programs, as California, New Jersey, and Rhode Island have done. These programs extend the TDI benefits beyond the employee’s own

non-job-related illness to care for spouses, domestic partners, or aging parents using nominal employee-only payroll deductions as their funding stream.

- **Consider and adopt options that protect family caregivers from discriminatory practices in the workplace.** With few exceptions, most federal and state statutes do not expressly prohibit family responsibility discrimination (FRD). There is a patchwork of federal, state, and local laws that together present a complicated legal environment for employers and employees alike. The lack of consistent policy leaves many working caregivers unprotected from FRD. It also leaves many managers and supervisors unaware of how eldercare affects their employees. State policymakers should consider whether a single statewide law would simplify and clarify the legal environment for employers while filling gaps in legal protections for employees with family responsibilities. One means of addressing FRD worth considering is to add family caregivers as a protected class to existing state law.
- **Ensure access to affordable eldercare options** to support workforce productivity and New York's caregivers. Just as affordable, accessible child care provides employees peace of mind at work and enhances their productivity, so too would affordable and accessible eldercare.

V. Ensure Access to Legal Services

In the listening sessions, caregivers raised a variety of legal issues related to finance and health. In many instances, caregivers did not know the wishes of their parents or relatives and felt they had waited too long before taking action, especially when a parent was diagnosed with Alzheimer's disease or another dementia. When dementia is involved, caregivers were concerned that their older relatives may be taken advantage of or make bad decisions about their investments. Participants also expressed fear that their elderly parents may be subjected to fraud or other unscrupulous financial transactions. The complications of not having all legal documents in place; such as living wills, health care proxies, HIPPA, medical orders for life sustaining treatments (MOLST), and powers of attorney; put caregivers in difficult situations.

Caregivers also discussed situations of contentious relationships among siblings, not being able to make rational decisions, or being concerned that the primary caregiver may not be acting fairly on behalf of the parent. Some caregivers were concerned about costs associated with hiring an attorney and preparing legal documents including guardianships and pooled trusts. Caregivers lamented that they were frequently confronted with making big decisions during times of crisis and the need for mediation and transparency among caregivers as future decisions were made.

Recommended Actions:

- **Enact legislation such as S.5779/A.7892** to allow banking institutions to protect the financial assets of vulnerable older adults, refuse to honor transactions that may result in financial exploitation, and contact a caregiver when there is unusual account activity.
- **Ensure access to competent legal assistance** through sufficient funding of the Aging Services Network and Legal Services and promote Governor Cuomo's new initiative to improve legal

services for vulnerable adults that SOFA, the State Office of Court Administration, and the New York State Bar Association are developing.

- **Explore partnerships with law schools**, under SOFA's leadership, to assist caregivers with the legal services and advice related to their caregiving responsibilities.

VI. Increase Affordable Housing and Transportation Options

Older adults wish to remain in their homes and communities for as long as possible. Caregivers indicated multiple reasons why remaining in one's own home may become difficult. They cited the high cost of maintenance, adapting homes to accommodate certain disabilities, unreliability and expense of transportation, and the ever-increasing cost of utilities and taxes. Homeowners often have the added burden of expensive and steadily rising homeowners' association fees. In many areas of the state, readily available, affordable, and safe housing for older adults is lacking.

Caregivers talked about the fear of their loved ones becoming isolated and homebound due to chronic conditions, disability, or lack of transportation.

Recommended Actions:

- **Expand and increase information about the Access to Home Program**, which provides interest-free loans to property owners to make dwelling units accessible for low- and moderate-income persons with disabilities and seniors with age-related disabilities. This assistance allows these vulnerable individuals to safely and comfortably continue to live in their residences and avoid institutional care.
- **Promote and increase a diverse range of stable, affordable housing options** that form the foundation that allows older adults to age in place and provide a critical support to family caregivers. Housing options should also let older adults be part of an active community that embodies elements of walkability, universal and inclusive design features, and accessible transportation. Attention should be given to older adults with low and moderate incomes and create more affordable choices. The housing options should include accessory apartments or in-law flats, multigenerational housing, housing with services, vertical and horizontal Naturally Occurring Retirement Communities (NORCs), co-housing that promotes active neighboring, and opportunities to pair older adults with others in their communities.
- **Increase and promote a diverse range of transportation options** through SOFA's direction that allow older adults to age in place and be part of an active community by empowering them to travel for both medical and social purposes. Transportation should accommodate caregivers who may need to accompany their loved ones and should be flexible enough to accommodate the real-life use requirements of consumers. Transportation for mobility-impaired consumers in particular should be examined to determine if needs are being met. Low-cost and flexibility are primary concerns of caregivers who often must step in to provide transportation when no options are available or the options that exist either do not meet the needs of their loved ones or are financially burdensome.

VII. Building Social Networks

Although many older adults are fully integrated into the community and have a significant network of family and friends to offer help and support, nearly 29% of older adults live alone. Other older adults may live a distance from their families, or their situations demand more help than can be offered by just one person. Additionally, some older adults are segregated from the broader community because of their housing situation, depression, fragility, chronic debilitating conditions, or lack of transportation. Cultural factors like language, nation of origin, and religion also factor into community integration. Within the LGBT community in particular, social isolation is a profound challenge faced by many family caregivers.

Caregivers attending the listening sessions shared the variety of innovative volunteer models that have been established in New York to help older adults and, subsequently, their caregivers. A number of these approaches have proven their effectiveness over time. Some programs use trained volunteers to perform simple, nonmedical tasks such as grocery shopping, bill paying, and medical escort services, thereby freeing up the caregiver. Importantly, individuals representing these caregiver programs emphasized that volunteers are not always free, and for these programs to succeed and thrive, they require an administrative host to recruit, orient, train, supervise, and coordinate them.

Recommended Actions:

- **Develop a pilot program** through SOFA to build social networks using both peer-to-peer and intergenerational approaches. These networks, based in nonprofits, houses of worship, and other organizations, can draw from volunteers within the communities where the older adults and their caregivers reside, thus promoting cultural responsiveness and customized care. Some of the best practice models that could be replicated include Share the Care (www.sharethecare.org), Time Dollars (www.timebanks.org), Mercy Care of the Adirondacks (www.adkmercy.org), Hearts and Hands: Faith in Action (www.hnhcares.org), Care Links (www.chsny.org/carelinks), SAGECAP (www.sagecap.usa.org/programs/sagecap.cfm), and Faith in Action (www.putyourfaithinaction.org).

VIII. Improving the Workforce

Family caregivers often cannot provide all the care all on their own. Frequently, they must rely on paid workers to augment the care they provide and to give them a break. The care provided by long-term services and supports direct-care personnel is only as good as the personnel who provide it. Workforce challenges, including how to best ensure the skills needed to provide high-quality care, abound and need to be addressed for New York State to meet the growing need for high-quality care. In the listening sessions, family caregivers expressed difficulties and frustrations with issues surrounding the availability, cost, hiring of, and working with long-term services and supports direct-care personnel.

High turnover of staff due to low wages, high travel costs, lack of career ladders, inadequate training, and other considerations was cited often. In addition, the insufficient number of bilingual workers and workers aware of and sensitive to different cultures were concerns expressed at some listening sessions.

Finally, caregivers identified the problem of having to use registered nurses to perform services that could be safely and more cost-effectively performed by direct care -workers.

Recommended Actions:

- **Document the shortage of workers and their training needs and support research** to identify effective ways to address these problems.
- **Evaluate the core training competencies** needed by personal direct-care workers and how such competency-based training should be provided.
- **Create incentives** for providers to hire bilingual workers when appropriate and train all staff to be culturally competent.
- **Initiate efforts to promote changes in the work environment** that encourage staff recruitment and retention.
- **Allow nurses to delegate and teach** to direct-care workers and family caregivers certain health-related tasks currently not allowed in New York State.

Conclusion

Caregivers provide help out of love, responsibility, and concern for their loved ones. Their goal, which is shared by New York State, is to keep their loved ones safe and living independently for as long as possible. At the same time, they experience stress and strain.

Many caregivers make multiple sacrifices to care for someone. Faced with a parent, spouse, or other loved one who needs help, caregivers frequently assume the job with limited knowledge of how to begin or what resources are available to help sustain them. Research shows that prolonged caregiving reduces personal time and energy for other family members. It can also produce emotional and physical stress, leading to increased health risks. In addition, the overwhelming responsibilities of prolonged caregiving place a burden on family finances, create workplace challenges, and can increase retirement insecurity.

Studies by SOFA and other research indicate that a variety of strategies, including support services for caregivers, can help mitigate the burdens of caregiving. As a result of these supports, caregivers become more confident and are able to provide care for a longer period of time, delaying or preventing institutionalization of a loved one. This saves taxpayers money because the majority of nursing home costs in New York are paid by the Medicaid program.

AARP New York, the Council of Senior Centers and Services of New York City, Inc., and the NYS Caregiving and Respite Coalition strongly believe that sound public policy supporting caregivers is a wise investment. The status quo in New York State is unacceptable. The four million families in New York providing billions of dollars' worth of care at home and the taxpayers who pay for expensive nursing home care deserve better.

APPENDIX A:

Text Version of Survey

Share with Us Your Experiences with Caregiving:

AARP New York, the New York State Caregiving and Respite Coalition, and the Council of Senior Centers and Services of New York City are exploring what more can be done to support the important work of family caregivers in New York State. Please take a moment to complete this short survey to share any ideas you have about how to improve the lives and work of family caregivers.

1. Are you a:

- current caregiver
- former caregiver
- person who is receiving care from a loved one
- a provider of services
- a friend or relative of a caregiver
- a person who works in public policy
- a provider of services for caregivers

2. Have you as a caregiver experienced challenges in providing care or arranging for services for the person you care for?

- yes
- no

3. If you answered "yes" to question 2, please share what challenges you have encountered.

4. As a caregiver, have you experienced difficulty with the following? (check all that apply):

- bathing
- dressing
- housekeeping
- housing
- information
- meals
- medical care management
- medication management
- personal finances
- respite
- social activities
- transportation
- other

5. What are some supports that you would like to see to assist you as a caregiver?

6. Are there changes in government policies, programs, or services that you can identify to give caregivers the services and supports they need?

APPENDIX B:

Expanded In-Home Services for the Elderly (EISEP) assists people aged 60 and older who (1) need help with everyday activities to take care of themselves (dressing, bathing, personal care, shopping, and cooking), (2) want to remain at home, and (3) are not eligible for Medicaid. EISEP services are intended to supplement, not replace, the care provided by family caregivers, and the program has cost share requirements based on a sliding fee scale.

Community Services for the Elderly (CSE) is a state aging services block grant that enables localities to determine specific unmet needs of older New Yorkers, enabling them to avoid unnecessary placement in institutional care. In state fiscal year 2011-12, approximately 66,000 older New Yorkers benefited from a wide range of CSE-funded services including case management, personal care, home delivered meals, information and assistance, referrals, social adult day care, transportation, respite, telephone reassurance and friendly visits, health promotion and wellness activities, senior centers, and other congregate programs.

REFERENCES:

AARP. (2011). *Valuing the Invaluable: 2011 Update - The Growing Contributions and Costs of Family Caregiving*.

AARP. (2013). *Home Alone: Family Caregivers Providing Complex Chronic Care*.

AARP. (2013). *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers*.

Center for Excellence in Aging and Community Wellness at the State University of New York, Albany. (2011). *Nursing Home Diversion Modernization Program, Final Evaluation Report*.

CSCS. (2009). *No Time to Wait: The Case for Long Term Care Reform. Recommendations for Modernizing Long Term Care in NY*.

MetLife Mature Market Institute National Alliance for Caregiving. (2006). *The MetLife Caregiving Cost Study: Productivity Losses to U.S. Business*.

MetLife. (2010). *The MetLife Study of Caregiving Costs to Working Caregivers: Double Jeopardy for Baby Boomers Caring for Their Parents*.

National Alliance for Caregiving (NAC) and AARP. (2009 November). *Caregiving in the U.S. 2009* (Bethesda, MD: NAC, and Washington, DC: AARP).

New York State Office for the Aging. (2009). *Sustaining Informal Caregivers New York State Caregiver Support Programs Participants Survey*.

New York State Office for the Aging. (2010). *Livable New York Resource Manual*.

For more than 50 years, **AARP** has been serving our members and society by creating positive social change. AARP's mission is to enhance the quality of life for all as we age, leading positive social change and delivering value to all people 50+ and to society through advocacy, service and information. The principles of collective purpose, collective voice and collective purchasing power guide our efforts. AARP works tirelessly to fulfill the vision of a society in which everyone lives their best life with dignity and purpose, and in which people can fulfill their goals and dreams.

Members of AARP span four generations and reflect a wide range of attitudes, cultures and lifestyles. Approximately one-third of AARP members work full- or part-time, while most of the remainder are retired (including career educators affiliated with NRTA: AARP's Educator Community).

AARP does not endorse candidates for public office or make contributions to either political campaigns or candidates.

AARP New York Legislative Office
One Commerce Plaza
Suite 706
Albany, NY 12180
(866) 227-7442
www.aarp.org/NY



Council of Senior Centers and Services of New York City, Inc. (CSCS) is a membership organization of more than 200 senior service agencies that serve over 300,000 senior citizens throughout New York City. Our goal is to ensure that the elderly of New York City receive quality services by helping senior service organizations build their capacity to provide superior programs and services through advocacy, training, innovative programming and the exchange of ideas.

CSCS
49 West 45th Street
7th Floor
New York, NY 10036
(212) 398-6565
www.cscs-ny.org



As a Core Team member of the Lifespan Respite Initiative in New York State, the **NYS Caregiving and Respite Coalition (NYSCRC)** has grown in its capacity to serve as a clearinghouse of information for professionals and for caregivers, providing support to individuals across the age and disability spectrums. It continues to expand partnerships and the range of information available about caregiving and respite activities across the state.

NYS Caregiving and Respite Coalition
1900 South Clinton Avenue
Rochester, NY 14618
(585) 244-8400
www.NYSCRC.org



