

A Plan to Support Unpaid Caregivers in New York City

2018

Contents

Background	1
The Future of Caregiving in NYC.....	3
Vision.....	4

Background

New York City is home to an estimated 900,000 – 1.3 million unpaid caregivers. Because of New York City's large and diverse unpaid caregiver population, as well as its growing population of seniors, now is the time to focus on their needs. The City is committed to providing a variety of services targeted toward caregivers, as well as other supports that have the potential to benefit caregivers. At the same time, there is opportunity to leverage existing resources to reach and serve more caregivers.

Caregivers often experience financial, physical, and emotional stress, and they often struggle to balance their work or personal lives with their caregiving responsibilities. They may sacrifice their own self-care in order to focus on caring for loved ones and often do not avail themselves of services simply because they do not know that services exist. Changing the status quo begins with empowering caregivers to ask for help and connecting them with the resources they need to live comfortably and the tools they need to provide the best possible care.

In response to Local Law 97 of 2016, the New York City Department for the Aging (DFTA) conducted a survey of unpaid caregivers in New York City. The purpose of the survey was to examine the extent to which unpaid caregivers' needs are met by existing services and to identify areas for improvement. There were three types of caregivers surveyed:

- Adults caring for family members aged 60 or older, including adults with Alzheimer's disease or other dementia;
- Grandparents or other older relatives who are the primary caregivers of children under 18; and
- Adults caring for individuals with disabilities between ages 18 and 59.

While some of the findings reflect the unique circumstances of each caregiver group, there are several shared characteristics and challenges among the three types of caregivers. Of all caregiver groups surveyed:

- Most are women and at least 50 years old.
- More than half provide at least 30 hours of care each week.
- At least one-third struggles financially.
- Information about available services is one of the top two most needed services.
- Respite care, which refers to services that give caregivers a temporary break from their caregiving duties, is one of the areas with the highest levels of unmet need. At least 1 in 4 needs but does not receive it.
- Lack of knowledge about available services and income/financial limitations are two of the most prevalent barriers to obtaining services.

Using the information collected by the surveys, the City engaged in a strategic planning process to chart a path for the future of caregiving in New York City. The plan developed during this process, detailed below, outlines broad goals to improve the lives of caregivers and proposes strategies to connect more caregivers to the services they need and deserve.

In October, following the completion of the study, the City convened a working group composed of representatives from agencies and external partners including DFTA, the Administration for Children's Services (ACS), Health + Hospitals (H+H), the Commission on Gender Equity (CGE), THRIVE, the Mayor's Office for People with Disabilities (MOPD), the Department of Education (DOE), the Office of Management and Budget (OMB), AARP, and City and State Legislative Affairs. To allow for more focused, in-depth discussions, the working group was divided into four sub-committees: Policy, Financial Stability, Services, and Communications. Members of the Communications sub-committee discussed different approaches to help New Yorkers better understand what constitutes caregiving and learn more about their rights as caregivers. The Policy sub-committee considered ways the City can leverage existing City, State, and Federal resources to help more caregivers get the services they need. Those on the Financial Stability sub-committee explored several strategies to help caregivers make ends meet. Finally, the Services sub-committee assessed the scope of services currently available to caregivers and identified where gaps exist.

Background, continued

Five principles guided the development of the recommendations, with each designed to be: 1) **Responsive** to the expressed needs of New York City's caregivers; 2) **Collaborative**, connecting City services; 3) **Pragmatic**, ensuring that the goals are achievable with existing tools; 4) **Stabilizing**, providing long-term stability for families; and 5) **Compassionate** toward the realities caregivers face.

After a series of conversations, further analysis of the survey findings, and taking inventory of current City services available to caregivers, the sub-committees worked together to figure out ways to address some of the primary challenges caregivers face.

This process is the first in many steps toward better serving the City's unpaid caregivers. According to Local Law 97, DFTA must survey caregivers again in two years and every five years thereafter. As such, the ideas in this document are intended to be practical enough to be implemented, but fluid enough to meet the evolving needs and demographics of unpaid caregivers in New York City.

The Future of Caregiving in NYC

Caregivers are on the frontlines of caring for our children, seniors, and people with disabilities, and their dedication and compassion help make New York City great. The City continues to support these New Yorkers using the tools of municipal government, including communication, advocacy, policy development, and interagency collaboration.

Recognizing that caregivers have different needs and challenges, the City has leveraged the resources and expertise of multiple agencies in order to best serve its caregivers. At the same time, improving the lives of caregivers requires a holistic approach that takes into account all aspects of caregivers' lives—how their financial, physical, and emotional challenges intersect.

The working group envisions a future in which caregivers in New York City:

- Identify as caregivers.
- Know what services are available and where to find them.
- Feel supported in balancing their work and personal lives with caregiving responsibilities.

These goals will continue to guide the City's efforts to develop policies and programs to improve caregivers' lives.

Vision

The working group proposes several strategies that could help realize the ideals outlined above. Each proposal was informed by survey findings and developed and refined during a collaborative process.

1. Leverage and expand awareness about existing resources for caregivers

While many caregivers do not know about services available to them, the City has made investments in caregiver support and has existing programs that have the potential to benefit caregivers. For example, the City recently committed to a major investment to help alleviate the needs of caregivers by doubling DFTA's current caregiver program from \$4 million to \$8 million and increasing funding for Home Care and Case Management services. DFTA also operates the Caregiver Resource Center, which consists of social workers who offer support to caregivers and provides consultation opportunities for professionals. In addition, the City's free mental health support hotline NYC Well can help caregivers experiencing stress and depression, while DFTA's Grandparent Resource Center provides support to older adult caregivers raising their grandchildren. Statewide, NY Connects employs a "no wrong door" approach to help connect New Yorkers with appropriate services. The working group recommends leveraging and communicating these and other resources to caregivers.

Still, challenges remain. Many caregivers do not know where to go for information about caregiving or whether they are eligible for services. To make services and information easier to find, the working group advises exploring strategies to help more caregivers access information about caregiving and the services available to them. These strategies could include efforts to make the process of locating services quicker and easier, as many caregivers are sent to various agencies and non-profits in search of help before locating the service they need or giving up entirely. The City should seek to limit the number of steps between when a caregiver reaches out and is connected with the information or services they require.

Additionally, the working group suggests leveraging several existing touchpoints within City agencies often not overtly associated with caregiving, including, but not limited to, the Department of Education—which has the ability to communicate with 1.1 million students and their parents or guardians—and Health + Hospitals, which serves more than one million New Yorkers annually across the City's five boroughs, including caregivers and care recipients. Within DOE, there are multiple opportunities for outreach, including leveraging the Citywide Education Council for District 75. District 75 is designed to serve students with disabilities, including those who are emotionally challenged or on the autism spectrum. Engaging this Council, whose key role is to consult with other parents within the community and provide insights on current education policies, could be a first step in speaking directly to parents and communities about caregiving. Using these channels, the City can amplify its messaging and help make services more accessible.

2. Encourage New Yorkers to identify as caregivers

Caregivers often do not recognize themselves as caregivers and thus often do not seek out the benefits and services for which they may be eligible. The working group suggests developing an outreach plan to raise awareness about the challenges caregivers face and the services that may alleviate those challenges. One aspect of an effective plan would be meeting the target audience where they are—a topic frequently discussed during Communications sub-committee meetings.

Communication in the form of strategic public messaging, as well as other mediums like photography and graphic design, should reflect the diversity of New York City, speaking to caregivers of different ages and ethnicities and depicting a range of caregiving situations and responsibilities. The goal should be to help more people recognize themselves as caregivers and empower New Yorkers to take the next step toward finding and obtaining services.

Vision, continued

3. Educate caregivers about best practices and techniques for providing care

Training is a broad field with many opportunities for caregivers. Caregivers often need access to information about how to give care, which may encompass everything from how to navigate health systems or legal services to providing care themselves. A lack of training and education can make caregivers feel overwhelmed or helpless. Training, formal or informal, has the potential to alleviate stress as well as provide a measure of financial relief, particularly if caregivers can be trained to do something they had previously hired a professional to do. Moreover, training caregivers to administer basic caregiving techniques like wound care or mental health first aid has the potential to greatly improve quality of care for their recipients.

As such, it is important to support training programs that help grandparents raising young children, people caring for seniors, and people caring for those with disabilities. While online modules have the potential to make training more accessible to caregivers pressed for time or far from where training is offered, in-person programs like Parenting the Second Time Around (PASTA) are also valuable. All trainings should also be culturally competent and tailored toward the needs of New York's diverse communities of caregivers.

Additionally, THRIVE NYC's Mental Health First Aid (MHFA) training includes content tailored to the needs of caregivers of older adults. The working group suggests making these trainings more readily available to both caregivers and City employees to help increase education and awareness of these important services.

4. Help caregivers access affordable transportation

Transportation was one of the most-frequently cited services with which caregivers experienced difficulties. Many caregivers, particularly those caring for older adults, expressed dissatisfaction with the limited and sometimes impractical transportation options available to them. Going places can be especially challenging for those who do not live near a bus or subway station. And even if there is a subway stop nearby, the station is sometimes inaccessible because there is no elevator. In the surveys, some caregivers said Access-a-Ride was unreliable.

Improving access to affordable transportation options would greatly benefit caregivers and their care recipients. Some progress has been made, including the Taxi and Limousine Commission's accessible dispatch which is now available in all five boroughs. Still, while end-to-end services exist, cost is a barrier for many. As a response to transportation issues for all residents, the City has advocated for a "millionaires tax" that would pay for subway improvements and reduce fares for more low-income riders, which would benefit caregivers. The working group supports continuing efforts to make transportation more affordable for caregivers and their care recipients so they can get where they need to go with the least amount of difficulty.

There is also an educational component to helping caregivers get the transportation services they need. During working group meetings, the inability to ride with grandchildren or other young people was highlighted as a barrier to using Access-a-Ride, when, in fact, it is the service's policy that anyone may ride with anyone they wish, as long as the guest is indicated during the reservation process. Transportation is a key service area that would benefit from not only the aforementioned public outreach and awareness among caregivers, but also from educating City employees about existing policies to help clarify and reduce false information.

Vision, continued

5. Support legislation that benefits unpaid caregivers

As home to a large population of caregivers, New York City is in a strong position to champion caregiving-related legislation at the State and Federal levels. Caregiving is a complex policy area that requires cooperation across all levels of government to find and implement creative, effective solutions. As such, the working group believes the Administration should take an active role in advocating for legislation or policy initiatives that would support New York City's caregivers.

6. Continue a working group focused on caregivers

Because of its large caregiver population and the diversity of caregivers' needs, a working group should continue to exist within the City to support and coordinate efforts for caregivers. This body, similar to the group that developed this document, could drive policy by studying the evolving landscape of caregiving in New York City and continuing to listen to and engage with the caregiving community.

7. Communicate affordable housing efforts and opportunities to caregivers

The City has taken steps to help seniors live affordably and age in place in New York City. Two key items are the passage of Zoning for Quality and Affordability and the ongoing implementation of the Mayor's housing plan.

Zoning for Quality and Affordability, approved by the City Council in 2016, included a provision to eliminate parking required for new, and in some cases existing, affordable senior housing developments (where residents often do not own cars), and a provision for increased FAR (floor area ratio) for affordable senior housing and care facilities to help provide a broader range of housing options for seniors. While challenges remain in this field, and more incentives could be implemented to encourage their development (including increased public funding), this is a step in the right direction.

In addition, the Mayor's "Housing 2.0" plan, released in Fall 2017, included a section about "putting seniors first." The City is doubling its efforts on senior housing to serve 30,000 households over the extended 12-year plan. The plan includes three key strategies: 1) HPD will develop a new assessment process that will be focused on accessibility, including changes from shower bars and accessible bathrooms; 2) NYCHA will create a "dedicated pipeline" of land through which HPD's Senior Affordable Rental Apartments program (SARA) can develop an expected 4,000 new homes for seniors; and, 3) the City will increase outreach and leverage federal programming.

The Administration is committed to increasing the amount of affordable and accessible housing for everyone. However, it is necessary to explore opportunities to improve or expand assisted-living communities.