



**TESTIMONY**

Presented by

**Robin Fenley, PhD, LCSW  
Deputy Assistant Commissioner, Long-Term Care**

on

**Oversight: Providing Support to New York City's Caregivers**

before the

**New York City Council  
Committee on Aging**

on

**Tuesday, December 9, 2014  
10:00 A.M.**

at

**250 Broadway, 14<sup>th</sup> Floor Committee Room  
New York, NY 10007**

Good morning, Chairperson Chin and members of the Aging Committee. I am Dr. Robin Fenley, Deputy Assistant Commissioner in the Bureau of Long-Term Care, and Director of the Alzheimer's and Caregiver Resource Center at the New York City Department for the Aging (DFTA). I am joined today by Kim Hernandez, Assistant Commissioner of Active Aging, and Giovana Montalvo Baer, Director of the Grandparent Resource Center. On behalf of Commissioner Donna Corrado, I would like to thank you for inviting us to testify on the topic of providing support to New York City's caregivers.

Millions of people throughout the U.S. are informal caregivers. More than 65 million individuals provide care for family members who are chronically ill, disabled or aged across the country. These caregivers assist family members by running errands, paying bills, preparing meals, picking up medications, helping with dressing and more. In New York State, there are an estimated 1.9 million caregivers. Approximately 1.5 million individuals serve as informal caregivers in New York City, recognizing that the number could be much larger, in that people often do not recognize that they are caregivers as well. The average time spent in providing care is 21 hours per week, which is, essentially, a second job for many caregivers. The economic value of these informal caregivers, should these services be provided by formal caregivers, is an estimated \$450 billion per year.

In addition, as of 2011, 2.7 million grandparents serve as the primary caregiver for their grandchildren. More than half of these grandparents—55 percent—have been serving as primary caregivers for three years or more, and 38 percent have been doing so for five years or more. One-fifth, or 22 percent, of grandparent caregivers are living below the federal poverty line, while 10 percent among the general population of individuals ages 50 and older are below the federal poverty line. In New York City, about 68,000 grandparents are raising grandchildren under 18 years old.

#### **NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM**

In 2000, the Older Americans Act (OAA) was amended for the first time in 25 years in response to the evolving needs of the older adult and the advocacy efforts of their caregiving family. The National Family Caregiver Support Program (NFCSP), Title III-E of the OAA, was enacted to

provide a full complement of service options to family members or responsible individuals who provide care for adults ages 60 and older, and to grandparents or older relatives who have primary responsibility for raising grandchildren ages 18 and younger. The 2006 reauthorization of Title III-E, in response to advocacy at the local and national levels, has now expanded the definition of those who may be served through this program to include younger grandparents, ages 55 and older, older adults with disabled children of any age, and families caring for individuals of any age with Alzheimer's disease or related neurological disorders.

The enactment of the NFCSP represented a significant departure from the historical approach to service delivery under the OAA. The legislation took an important step toward dismantling the funding silos of the aging, mental health and disability communities. The program also expanded the target population for aging services by identifying the caregiver as the primary recipient of services instead of designating the care receiver as the exclusive service beneficiary. This recognition of the interrelated nature of caregiving made the provision of direct services possible for caregivers themselves, such as support groups and trainings on aspects of care and how to manage their care responsibilities.

Critical services and community linkages are offered under the NFCSP to those who are caring for family members at home. The value of addressing the bio-psychosocial needs of informal caregivers is well documented. Maintaining the optimum health of the caregiver has been repeatedly demonstrated to delay the institutionalization of the care receiver and to reduce levels of caregiver and family stress. The importance of supporting caregivers is underscored by the growing cadre of caregivers who are employed, raising their own families, and now find themselves caring for older relatives. Unfamiliar with the kinds of service options available to meet their caregiving needs, these individuals often find themselves confronting competing demands from their job, family obligations and caregiver responsibilities.

The intent of the NFCSP as implemented by Area Agencies on Aging (AAAs), of which DFTA is the largest AAA in the U.S., is to provide "one-stop shopping" so that the needs of caregivers can be assessed and addressed through information, education and service linkages for themselves and their care receivers. There are five service categories authorized under the

NFCSP: 1) information about services; 2) assistance with accessing services; 3) individual counseling, support groups and training; 4) respite care; and 5) supplemental services.

Respite care involves services such as congregate care for the care recipient, in-home care and institutional overnight stays. In order to be eligible for respite care, the care receiver must be impaired in at least two activities of daily living (ADLs) – that is, he or she must need physical assistance, verbal cueing, or extensive supervision in order to bathe, dress, eat, ambulate or toilet.

Under supplemental services, which are designed to provide non-traditional assistance, the requirement for two ADLs also applies. Examples of supplemental services can include purchase of incontinence supplies or medications, minor home modifications and transportation. Caregiver clients are empowered to identify their care needs, while working with a case manager who acts as a liaison to the provider of service.

The ADL stipulations do not apply to the grandparent seeking respite or supplemental services for the grandchild. Respite and supplemental services in this instance can include summer sleep-away camp and tutoring services, respectively. It is important to note that funding for respite and supplemental services is limited, with the judicial expenditure of these funds incumbent upon each caregiver program.

#### **ALZHEIMER'S AND CAREGIVER RESOURCE CENTER**

DFTA has contracted with community based organizations (CBOs) citywide since 2001 to provide services under the National Family Caregiver Support Program. Currently funded at \$4 million for FY '15, DFTA's ten caregiver programs have served approximately 9,000 individuals throughout the City since July of this year, providing information about caregiving, discussing the associated stressors and offering other pertinent resources. Other caregivers have received counseling and have participated in support groups and trainings through these programs.

Seven of the ten DFTA sponsored caregiver programs serve designated catchment areas. Of these seven programs, three serve grandparents raising grandchildren, in addition to working with adult child and spousal caregivers. We also have programs that assist caregivers citywide:

one program serves Chinese, Japanese and Korean caregivers; another program serves the blind and visually impaired; and a third program serves the LGBT caregiving community. In terms of language access, caregiver services are provided to individuals who speak Spanish, Russian, Polish, Ukrainian, Filipino, Greek, Mandarin, Cantonese, Korean and Japanese. Language line is available for other languages or dialects. All programs provide ongoing community educational forums on topics related to caregiving and the many aspects of long term care. Collaborative caregiver public forums have been successful outreach opportunities, in addition to the provision of information.

It is important to note that included among the caregivers served are long-distance caregivers who live out of state or out of the country, working caregivers, and more recently, young caregivers – that is, children who have become caregivers for their parents or other relatives. Each type of caregiver has their own unique concerns and situations, with the commonality of providing care for a loved one crossing all caregivers, working to allow the care receiver to remain at home and in their community.

DFTA is also a member of a number of caregiver coalitions. The State appointed DFTA as a member of the New York State Family Caregiver Council in 2007, which conducted the first New York State caregiver survey on the impact of NFCSP services. DFTA is involved in the New York State Office for the Aging's Caregiver Coordinators group, and has presented in numerous venues and areas of the State on issues facing the diversity of New York City caregivers. Additionally, EmblemHealth launched the New York City Family Caregiver Coalition in 2006, which now resides with the Council of Senior Centers and Services. DFTA participated in the early development of the Coalition. In January 2015, Commissioner Corrado will co-chair a meeting hosted by the New York City Partnership for Family Caregiving Corps, which will welcome a number of corporations, partnering in the creation of responsive guidelines for corporations that are increasingly encountering the working caregiver. You will hear more about this partnership today from Greg Johnson who will testify on behalf of EmblemHealth.

## **GRANDPARENT RESOURCE CENTER**

Years ago, DFTA recognized that an increasing number of the City's older adults were caring for their grandchildren or other young relatives, and responded with programs to support them. The Grandparent Resource Center (GRC)—the first of its kind in the nation—was established by DFTA in 1994. The Grandparent Resource Center provides a number of supportive services to those older adults who are raising grandchildren and other young relatives. Resource specialists at the GRC offer advocacy and case assistance, as well as referrals to appropriate community based organizations. These CBOs provide services such as: preventive services, legal services, financial assistance, advocacy, educational services, tutoring services for children, family counseling, and support groups.

In addition, the GRC holds workshops on topics such as financial entitlements; mental health and wellness; grandparent empowerment; kinship foster care, adoption, and child custody options; and navigating the City's child welfare system. The GRC also sponsors a resource library, holiday toy drive, and recreational activities for grandparents and their grandchildren. Finally, the GRC facilitates and provides information about community support groups for grandparents raising grandchildren. In fact, the GRC sponsors a network for grandparent support group facilitators, which cultivates the exchange of ideas, event collaboration and specialized trainings. The GRC has worked to provide information and referrals, case assistance and trainings. Working with community partners, the GRC organizes educational forums and events for the grandparent caregiving community. GRC presentations and trainings for caregivers are held at local schools, hospitals, churches and other religious institutions. From 2013 to 2014, there were 677 new grandparent caregivers served, and 541 participants in GRC sponsored support groups held in different neighborhoods in the City. Through the GRC, 764 grandparent caregivers received information during that period.

DFTA has made efforts to create a one-stop point of reference for kinship care providers through the GRC. For kinship caregivers who prefer using a resource manual, DFTA provides resource guides that outline benefits and services available to kinship caregivers, and how to access these services. The Resource Guide and Support Group Guide for Grandparents Raising

Grandchildren are available on the DFTA website, and are distributed at outreach events and through DFTA's network of aging services providers.

In order to serve some of the neediest kinship caregiver families, the GRC program has most recently expanded in July of this year under the Mayor's New York City Housing Authority (NYCHA) Anti-Violence Program. The GRC received \$472,000 in FY '15 for DFTA Community Advocates to work with residents at 15 NYCHA developments and provide resources and services to grandparent caregivers. Through the initiative, grandparent caregivers will receive grandparenting education, trainings and peer support on raising children.

#### **CONCLUSION**

Thank you again for this opportunity to provide testimony on supporting New York City's caregivers. I am glad to answer any questions you may have.

**COUNCIL OF THE CITY OF NEW YORK  
COMMITTEE ON AGING  
COUNCILWOMAN MARGARET CHIN, CHAIR**

**TESTIMONY**

**Providing Support to New York City's Caregivers**

**DECEMBER 9, 2014**

**For further information, please contact:**

**Judy Willig**

**Executive Director**

**Heights and Hills, Inc.**

**(718) 596-8789**



Thank you for the opportunity to speak here before you today. My name is Judy Willig and for the past 28 years I have been the Executive Director of Heights and Hills (HH), a 44 year old community based organization that annually serves 4,000 older adults and their families in 19 neighborhoods in Brooklyn. Our mission, *to promote successful aging in the community*, is guided by a set of 8 beliefs, among them:

- Older adults are entitled to live as independently as possible, with dignity and personal choice
- Support for caregivers helps bind generations and improves outcomes for all

HH services include case management, caregiver support services, community care transitions, transportation, and volunteer services to homebound seniors, as well as community organizing and advocacy on behalf of community-dwelling older residents.

### **Services Available**

Each year Heights and Hills provides ongoing services to over 500 informal family caregivers and provides one-time information and referral services to many hundreds more. Our program provides support to families through the provision of information, crisis intervention, referrals, in-depth assistance accessing entitlement and benefits, one-on-one supportive counseling by professional social workers, multiple support groups for family caregivers – including a support group for spouses of people living with Parkinson's Disease, a support group specific to daughters of parents living in assisted living facilities, and a telephone support group in the evenings for working caregivers. We also provide educational seminars in the community that include:

- *Caregiving 101*
- *Caregiving for the Sandwich Generation*
- *How to Care for Your Loved One When They are Not So Lovable*
- *Understanding Dementia*
- *Caregiving and Family: Staying Sane When Everyone is not on the Same Page*
- *Long Distance Caregiving*, and
- A six-part series on dementia for Spanish-speakers in collaboration with the Alzheimers Assoc.

Two other critical components of our caregiver support program are respite care – a few hours a week of home care that allow the caregiver to take some time for themselves, and our supplemental service – which is a fairly flexible fund that allows for financial assistance for the purchase of necessary items – e.g. personal emergency response systems, nutritional supplements, transportation to and from support group meetings, payment for a nurse to complete the evaluation necessary for nursing home admission, and other one-time items that might assist a caregiver in their caregiving role.

Heights and Hills works hard to integrate our all of our programs to provide seamless service to our clientele. That said, fully 30% of our caregiver clients are referred by staff from our other programs, most notably from case management and Bridge to Home, our care transitions partnership with NY Methodist Hospital. Other referrals come through 311, from DFTA, from professionals in the community and many come by word of mouth, particularly from other caregivers.

## Caregiver Needs

A huge and long-standing issue in caregiving is the lack of self-identification. Most people don't think of themselves as "caregivers", but rather as just doing what is necessary for someone they care about. They fall into the role gradually, caring for a loved one as needs increase until they reach a breaking point and suddenly realize they are overwhelmed and in over their heads. Other caregivers step into the role because of an event, such as a health crisis, a hospitalization, or a sudden change in functioning in their loved one. But sometimes the crisis is a health event for the caregiver herself.

Research has shown that caregivers are more likely to have symptoms of depression or anxiety, are more likely to have long-term medical problems, have higher levels of stress hormones, have higher levels of obesity, and may be at higher risk for mental decline. One research study found that elderly people who felt stressed while taking care of their disabled spouses were 63 percent more likely to die within 4 years than caregivers who were not feeling stressed.

Part of the reason that caregivers often have health problems is that they are less likely to take good care of themselves. Caregivers are short on time, energy and money, given caregiving responsibilities that are often in addition to managing jobs and other family responsibilities, including taking care of children.

The needs of caregivers vary greatly and the need for flexibility in addressing those needs is critical. The age of the caregivers we see varies, as do the issues of the care recipients. We serve slightly more adult children who are employed, but almost as many spouses. The most common issues of care recipients are those related to long-term chronic illnesses and age – Alzheimer's and other forms of dementia, Parkinson's Disease, strokes, or just general decline in function related to advanced age (we have one care recipient who is 111), but we also see caregivers struggling with more acute situations, such as cancer or some other acute illness. Many come to us at a time of care transition – discharge home from the hospital or a rehab facility, or the opposite – the caregiver needs help understanding what is involved in nursing home placement - how to choose and evaluate, financial assistance, etc.

Across the board, the greatest problem identified by our caregivers is the lack of adequate resources for their older loved ones. Except for the very wealthy, we have limited options in this city for those who need ongoing daily care. Few have long term care insurance and that situation is not going to change anytime soon. While Medicaid is the major public payer for long term care, with managed long term care Medicaid now provides less care for those with chronic needs and it is the informal family caregivers who fill in the gaps. For those above Medicaid eligibility, private pay home care is extremely expensive and many families resort to the underground economy, hiring off-the-books, unregulated individual providers, if they can afford it. Family members often wind up financially supplementing their loved one's care, draining their own resources and retirement savings. Assisted living offers even less in the way of options. There are very few assisted living facilities that accept Medicaid or are subsidized, and the private pay options range anywhere from \$4,000 - \$9,000 per month for basic services of room

and board plus activities. These facilities have very minimal oversight and though some are licensed, standards are minimal. And nursing home costs in NYC are now at roughly \$140,000/year.

### **Recommendations:**

#### **Funding:**

- Caregiver support services are critical, but underfunded. We need to add funding to provide more of the services I have mentioned above.
- In addition, services like home delivered meals, adult day care, EISEP home care, senior centers, case management all supplement what families are already providing allow them to go on. We need to strengthen the aging services network, which provide respite and peace of mind for family caregivers.

#### **Legislation:**

- Family leave and workplace flexibility are necessary to allow working family members (mostly daughters) to take care of the needs of their loved ones, while remaining in the workforce.
- Family caregivers need training to manage complicated medical needs of loved ones upon discharge from the hospital. There needs to be legislation to require hospitals to identify the caregiver and train them before the patient is discharged.

#### **Public Services Campaign:**

- It would be extremely beneficial for the City to launch a public services campaign to let people know what caregiving is, and that there are resources out there for them and their elderly loved ones. So many of our caregivers just aren't aware of services like home delivered meals, access a ride, or how to apply for Medicaid and other benefits.

Finally, a word about flexibility. The majority of care for elders in this country still falls on family and that will continue as the baby boomers age. Services must be made to fit caregiver needs at the time and place that they need them, with a minimum of bureaucratic red tape. We have recently learned that DFTA is soon to implement more regulations that will require caregivers to submit to regular assessments and additional information gathering and questioning. While we know that collecting data about the people we serve is critical, we need to be very careful not to drive caregivers away by adding to their burden in our efforts to assist them.

It is in government's best interest to support families and provide them with the tools they need. Not only is it cost-effective, it is the right thing to do.



**New York City Council**

**Committee on Aging**

**Oversight: Providing Support to New York City's Caregivers**

**Tuesday, December 9, 2014**

*Remarks on behalf of JASA by Molly Krakowski, JASA Director of Legislative Affairs*

First, I want to thank Council Member Chin, Chair of the City Council Committee on Aging, for holding this important hearing on providing support to New York City's caregivers, and for allowing me to submit this testimony on behalf of JASA. I am Molly Krakowski, JASA Director of Legislative Affairs.

JASA's mission is to sustain and enrich the lives of the aging in the New York metropolitan area so that they can remain in the community with dignity and autonomy. In support of this mission, JASA offers a broad continuum of services to support elders as they age in their homes and communities. A critical component is the DFTA-funded Caregiver Respite Program in Brooklyn. Through this program, JASA assists more than 1,000 individuals each year, helping family caregivers with such services as in-home and group respite care, individual counseling, access to benefits and entitlements, purchases of daily care supplies, installation of home modifications to improve home safety, and peer-oriented caregiver support groups. Through educational outreach, **JASA's Brooklyn Caregiver Respite Program** also promotes community awareness about family-caregiver/care-recipient needs and available resources.

JASA staff helps families avoid potential crises (for example, developing and overseeing an alternate care plan when the caregiver is scheduled for surgery) and conducts individualized planning for long-term care needs. It has been our experience that homecare is the service most requested to alleviate the caregiving burden -- but homecare is expensive -- and the hours available through the Caregiver Respite Program are very limited. The increase in life expectancy, the cumulative growth of the 85+ age group, and the concurrent increase in functional disability, point to a potential impending crisis in homecare need.

However, there are other strategies to alleviate caregiver burden. In 2009, with funding from UJA-Federation of New York, JASA initiated a volunteer-based caregiver assistance project, the Caregiver Mentor Cooperative, engaging experienced former family caregivers to provide emotional and practical support to family caregivers new to

the experience. The project provided the opportunity to validate the former caregivers' efforts and to enhance the skills and capacity of the new caregivers. Approximately 60 successful mentor-volunteer/new-caregiver matches were achieved during the three-year pilot project period.

In the spring of 2013, JASA secured a grant from the MetLife Innovations in Caregiving Program to pilot **JASA Connections** in several Brooklyn communities. This project incorporated elements of the JASA Caregiver Respite Program's mentoring partnership and expanded it to include an evidence-based project, the **JASA Home Based Activity Program for Persons with Dementia**. The goal of this program was to improve the quality of life for caregivers and persons diagnosed with Alzheimer's disease and related disorders through a partnered volunteer in-home intervention.

During its short existence, JASA Connections successfully identified and matched thirteen volunteer-mentors and family caregivers, and there are three more are currently in process. Volunteers received training on symptoms of dementia and Alzheimer's disease, techniques for matching activities to the functional capacity and interests of the care recipient, and confidentiality regulations. The volunteer-mentor conducted eight in-home sessions with the caregiver and the care recipient. During these sessions, the volunteer demonstrated to the caregiver strategies for engaging the care recipient in meaningful activities (e.g., creating memory boxes with life mementos, movie viewing and discussion, specific period music listening, word search games, etc.) to support the remaining strengths and meet the changing needs of their loved ones. A report was submitted to MetLife this past September at the close of the program, and we would be happy to share it with this Committee.

While we appreciate the DFTA funding that allows JASA to offer a range of services available to support caregivers through the Brooklyn Caregiver Respite Program, we have sought innovative initiatives to expand the "reach." These initiatives need modest financial support from the City to implement them in a more sustainable and comprehensive manner, for example, a coordinator to recruit, train, and supervise volunteer-mentors. Volunteers are an enormous resource and this work is a validating, fulfilling experience.

Support for family caregivers is a vital component of a caring society's commitment to its aging members. It saves public money and deflects unneeded use of hospital emergency rooms, nursing homes, and other costly institutions. It allows family members to play an active role in caring for their loved ones. And, it supports those loved ones in aging at home with dignity and autonomy, a goal we all share.

We hope this hearing leads to further discussion of the important issue of support for caregivers and an openness to proposals to fund proven programs and new initiatives.

Thank you.

**TESTIMONY  
CITY COUNCIL COMMITTEE ON AGING  
HEARING**

**DECEMBER 9, 2014**

**10:00 A.M.**

**Marie Ellen Galasso, LMSW**

**Director of Social Services**

**Services Now for Adult Persons, Inc.**

**(SNAP)**

**80-45 Winchester Boulevard**

**Building # 4 CBU # 29**

**Queens Village, N.Y. 11427**

**Phone: (718) 454-2100**

**Fax (718) 740-4999**

**[www.snapqueens.org](http://www.snapqueens.org)**

GOOD MORNING DISTINGUISHED MEMBERS OF THE CITY COUNCIL COMMITTEE ON AGING, THANK YOU FOR CONDUCTING THIS HEARING THIS MORNING. MY NAME IS ALICIA FRY I AM THE CLINICAL CASE MANAGEMENT DIRECTOR OF SERVICES NOW FOR ADULT PERSONS, INC (SNAP). I AM HERE REPRESENTING MARIE ELLEN GALASSO. SHE IS SNAP'S DIRECTOR OF SOCIAL SERVICES AND OVERSEES SNAP'S CAREGIVER PROGRAM. SHE IS ALSO THE CHAIR OF THE NEW YORK CITY FAMILY CAREGIVER COALITION A PROGRAM OF COUNCIL OF SENIOR CENTERS AND SERVICES AND IS FAMILIAR WITH CAREGIVER ISSUES BOTH PROFESSIONALLY AND PERSONALLY.

THE ISSUE OF CAREGIVING IN NEW YORK CITY AND ACROSS THE NATION IS QUICKLY BECOMING ONE OF THE MOST CRUCIAL ISSUES OF OUR TIME. WITH APPROXIMATELY 42 MILLION PEOPLE PROVIDING CARE FOR A RELATIVE OR FRIEND WITH A CHRONIC HEALTH CONDITION IT BECOMES QUITE EVIDENT THAT WE MUST BE **PRO-ACTIVE** IN OUR SUPPORT OF INFORMAL CAREGIVERS BEFORE WE FIND OURSELVES **REACTING** TO A CRISIS OF EPIDEMIC PROPORTIONS. IN FACT I SUSPECT THAT WE WOULD BE

HARD PRESSED TO FIND SOMEONE WITHIN OUR OWN PERSONAL CIRCLES WHO HAS NOT PROVIDED CARE FOR A LOVED ONE OR FRIEND AT SOME POINT IN TIME.

THE CURRENT CAREGIVER SUPPORT FUNDING SERVICES COME THROUGH THE FEDERAL OLDER AMERICANS ACT AND ALLOW COMMUNITY AGENCIES LIKE SNAP TO PROVIDE CAREGIVERS WITH NEEDED SUPPORTIVE SERVICES SUCH AS: COUNSELING, SUPPORT GROUPS, TRAININGS, LIMITED/TEMPORARY HOME CARE AND OR GROUP CARE FOR CARE RECEIVERS, WHICH ALLOWS CAREGIVERS TO HAVE A RESPITE FROM THEIR CAREGIVING RESPONSIBILITIES. WHILE THESE SERVICES ARE HELPFUL BUDGETS ARE SORELY LIMITED. TO GIVE A BETTER PERSPECTIVE OF BUDGET LIMITATIONS, IN ORDER FOR SNAP TO PROVIDE RESPITE SERVICES TO ALL OF THE CAREGIVER CLIENTS REQUESTING THEM, RESPITE CAN BE OFFERED ONLY TWICE A MONTH UP TO A MAXIMUM OF APPROXIMATELY THREE MONTHS. THE NEED FOR CAREGIVER SUPPORT FAR OUTWEIGHS THE CAPACITY TO PROVIDE SERVICES. THE ENORMITY OF THIS ISSUE



SPEAKS TO THE NECESSITY OF INCREASING AND BASELINING CAREGIVER SUPPORT FUNDING.

IT SHOULD BE NOTED THAT CAREGIVER SUPPORT **AND** AGING SERVICES COMPLIMENT ONE ANOTHER. SERVICES FOR OLDER ADULTS SUCH AS CASE MANAGEMENT, HOME DELIVERED MEALS, HOME CARE AKA (EISEP), AND SOCIAL ADULT DAY CARE NOT ONLY HELP THE OLDER CLIENT BUT ASSIST THE CAREGIVER IN KEEPING THEIR LOVED ONES IN THEIR HOME. FUNDING FOR BOTH CAREGIVER SUPPORT AND AGING SERVICES HELP KEEP OLDER ADULTS IN THE COMMUNITY. THIS IS FAR LESS COSTLY THAN PLACING A LOVED ONE IN AN INSTITUTIONAL SETTING SUCH AS A NURSING HOME AND REPRESENTS THE WANTS OF THE MAJORITY OF OLDER ADULTS.

ACCORDING TO A RECENT NATIONAL SURVEY, DUE TO CAREGIVER RESPONSIBILITIES, 1 IN 5 CAREGIVER RETIREES LEFT THE WORKFORCE EARLIER THAN THEY PLANNED. 7 IN 10 HAD TO MAKE WORK ADJUSTMENTS WHICH INCLUDED CUTTING BACK ON WORK HOURS, CHANGING JOBS AND OR STOPPING WORK COMPLETELY.

LOW INCOME WORKERS, WOMEN AND MINORITIES WERE OFTEN THOSE LIKELY TO REDUCE WORK HOURS OR LEAVE THE WORKFORCE COMPLETELY DUE TO CAREGIVING NEEDS. WITHOUT SUPPORT, CAREGIVING IS NOT ONLY FINANCIALLY COSTLY ON THE SYSTEM BUT PERPETUATES POVERTY FOR THE FUTURE AS CAREGIVERS FOREGO PRESENT EARNINGS AND FUTURE SOCIAL SECURITY BENEFITS. THESE REDUCTIONS IN WORK HOURS CAN HAVE LONG TERM DETRIMENTAL CONSEQUENCES. THIS SPEAKS TO THE NEED FOR STATE LEGISLATION TO EXPAND BOTH PAID AND UNPAID FAMILY LEAVE WHILE ALSO ADDRESSING THE NEED FOR WORKPLACE FLEXIBILITY.

ACCESS TO AFFORDABLE LEGAL ASSISTANCE ALONG WITH TRAINING FOR CAREGIVERS FROM HOSPITAL EMPLOYEES AT DISCHARGE ARE ALSO WAYS TO SUPPORT FAMILY CAREGIVERS TO DIMINISH BOTH EMOTIONAL AND FINANCIAL STRESS.

PROVIDING SUPPORTIVE SERVICES FOR CAREGIVERS IS KEY TO THEIR WELLBEING AND DEMONSTRATES FISCAL AND MORAL RESPONSIBLITLY AND INTEGRITY.

WE APPRECIATE HAVING THE OPPORTUNITY TO SPEAK TO ALL OF YOU TODAY AND KNOW THAT YOU WILL WORK HARD ON BEHALF

OF CAREGIVERS IN NEW YORK CITY AND THROUGHOUT THE  
STATE.



**LEGAL  
SERVICES**

**INCORPORATED**

**TESTIMONY  
ON  
KINSHIP CAREGIVER SERVICES**

**BEFORE:**

**NEW YORK CITY COUNCIL  
COMMITTEE ON THE AGING**

**PRESENTED BY:**

**BARBARA GRAVES-POLLER  
*SUPERVISING ATTORNEY*  
MFY LEGAL SERVICES, INC.**

**December 9, 2014**

**MFY LEGAL SERVICES, INC., 299 Broadway, New York, NY 10007  
212-417-3700 [www.mfy.org](http://www.mfy.org)**

Thank you for affording our organization an opportunity to testify today. My name is Barbara Graves-Poller, and I supervise the Kinship Caregiver Law Project at MFY Legal Services. MFY envisions a society in which no one is denied justice because he or she cannot afford an attorney. To make this vision a reality, for over 50 years MFY has provided free legal assistance to residents of New York City on a wide range of civil legal issues, prioritizing services to vulnerable and under-served populations, while simultaneously working to end the root causes of inequities through impact litigation, law reform and policy advocacy. We offer advice and representation to nearly 10,000 New Yorkers each year. MFY’s Kinship Caregiver Law Project represents and counsels New Yorkers who serve as *de facto* parents for non-biological children. MFY is the only civil legal services organization in the city that has a program dedicated to kinship caregiver issues. We also co-chair the New York City KinCare Task Force, a group of advocates, representatives from City agencies, and social service providers who gather to address policy issues and service coordination for kinship care families.

While most of my comments will focus on the Grandparent Resource Center (“GRC”)’s work with kinship caregivers, I would like to note that MFY also works closely with the Department for the Aging (“DFTA”) to serve the legal needs of seniors to ensure that they age in place with dignity. Much of this work involves representing seniors in eviction proceedings so they do not lose their apartments and become forced to live in institutional and costly facilities such as nursing homes and adult homes, as well as obtaining government benefits, including home care, to ensure they can maintain their community housing. In addition, we represent seniors with disabilities who need modifications to their apartments in order to accommodate age-related disabilities.

### **I. Kinship Caregivers and the Need for Supportive Services**

In New York, as in other areas of the country, the need for kinship care most often arises in communities with high levels of poverty, teen pregnancy, mental illness, parental incarceration, and inadequate family support services. Approximately 75% of all caregiving grandparents live near or below the poverty line. Throughout the state, an estimated 80% of all kinship caregivers are African-American or Latino, 64% are unmarried women, and 85% receive no financial support from the child’s parents. Anecdotal evidence suggests that caregivers in New York City are both younger and poorer than their statewide counterparts. This combination of factors places low-income, kinship care families at extreme risk of replicating the cycle of intergenerational poverty.

While there are many benefits to these kinship arrangements, relative caregivers face a host of challenges in caring for their families. These are usually families with insufficient resources. Kinship caregivers are more likely to be poor, single, older, less educated, and

unemployed than heads of households in which at least one parent is present. They are also households in which the adverse experiences suffered by children and the emotional trauma and stressors caregivers face impair the family’s mental and physical health. The holistic legal services that we offer through our relationship with DFTA and other supportive service providers are essential to preventing these families from suffering additional crises.

## **II. DFTA’s Leadership on the NYC Kinicare Task Force**

For years, representatives from DFTA’s Grandparent Resource Center, including Helen Flowers and Brandy Orange, have played a key role in advancing policies to support caregivers by participating the New York City Kinicare Task Force. Not only do they help to shape the Task Force’s efforts to reform procedures at the Administration for Children’s Services and the New York City Housing Authority that disadvantage relative caregivers, they help to coordinate *PASTA* (“Parenting a Second Time Around”) trainings and actively assist relatives in individual cases. They frequently refer clients in need of legal representation to MFY after helping those individuals with benefits problems and in securing connections to health services. In cases where MFY is unable to offer representation due to capacity or conflicts reasons, DFTA assists these family members who are not otherwise eligible for legal counsel within the courts.

## **III. Gaps in Existing Services**

The Grandparent Resource Center provides high quality and urgently needed support to an underserved population. Unfortunately, it lacks sufficient resources to adequately serve all of the caregivers throughout New York City. While city agencies maintain no official count of the number of children living with relatives outside of the formal foster care system, social service providers estimate that more than 100,000 children in New York City live in kinship care arrangements. The GRC lacks the staffing and funding to meet the needs of this diverse and geographically dispersed population.

The second significant gap in the Grandparent Resource Center’s services relates to the fact that many caregivers are not grandparents or senior citizens. Approximately 60% of the caregivers in New York State are grandparents. The remainder includes aunts, cousins, siblings, god-parents, and a host of other relatives. While some of those caregivers may be fifty years of age or older, I regularly encounter caregivers, including some grandmothers, who are not senior citizens. For example, one of our current clients is a 28-year-old Bronx resident who has been caring for his three younger brothers without any financial support or legal order of custody for the children. Another client is a 43-year-old grandmother in the Bronx who needs help raising a grandchild recently born to her incarcerated daughter. We know from our years of working with DFTA that these caregivers would not be turned away if they seek assistance from the GRC.

However, since the center is housed within an agency dedicated to senior services and has a name that appears to limit services to grandparents, these clients would naturally conclude that they are ineligible for the GRC's assistance.

#### IV. Recommendations

MFY greatly appreciates the work that DFTA's Grandparent Resource Center does to assist kinship caregivers throughout New York City. To improve its effectiveness, we offer the following recommendations:

- **Increase service:** As stated above, the GRC's limited resources prevent the agency from fully serving New York City's caregivers. This high-needs population is not entitled to legal counsel and often faces barriers when trying to access public benefits and supportive services from City agencies. Accordingly, more resources should be allocated to the GRC to assist with non-legal advocacy and service coordination for these families.
- **Expressly include non-grandparent caregivers:** Close to half of all kinship caregivers are not grandparents, and a significant percentage are not senior citizens. Consequently, the GRC should consider revising its name, outreach materials, and 3-1-1 listing to encourage younger grandparents and other relative caregivers to avail themselves of the GRC's preventative and supportive services.
- **Clarify there is no age requirement to be served by DFTA as a kinship caregiver:** Kinship caregivers of all ages struggle with similar legal, financial, and health-related challenges and without adequate resources. In practice, GRC has been assisting caregivers of all ages to overcome these challenges. Therefore, GRC should revise its outreach materials and 3-1-1 listing to encourage younger caregivers to take advantage of the center's services.

Once again, thank you for allowing us to speak about these important issues today. MFY is available to take referrals and to provide additional information on caregiver legal concerns. We are also happy to assist caregivers in your respective communities.



Selfhelp Community Services, Inc.  
520 Eighth Avenue  
New York, NY 10018  
212.971.7600

**Testimony from Selfhelp Community Services, Inc.  
New York City Council Committee on Aging  
December 9, 2014**

**Good Morning.**

**My name is Erin Brennan. I am the Program Director of the Selfhelp Alzheimer's Resource Program, which we call SHARP.**

As you may know, Selfhelp was founded in 1936 to help those fleeing Nazi Germany to maintain their independence and dignity as they struggled to forge new lives in America. Today, Selfhelp has grown into one of the largest and most respected not-for-profit human service agencies in the New York metropolitan area, with 26 sites throughout Manhattan, Brooklyn, Queens, the Bronx, and Nassau County. Selfhelp provides a broad set of important services to more than 20 thousand elderly, frail, and vulnerable New Yorkers each year, while remaining the largest provider of comprehensive services to Holocaust survivors in North America. Selfhelp offers a complete network of community-based home care, social service, and senior housing programs with the overarching goal of helping clients to live with dignity and avoid institutionalization.

Our services are extensive and include:

- Specialized programs for Holocaust Survivors;
- Nine affordable senior housing complexes;
- Four Naturally Occurring Retirement Community (NORC) programs;
- Two DFTA funded case management;
- Five senior centers including one of New York City's first Innovative Senior Centers;
- Home health care;
- Client Centered Technology Programs including the City's first Virtual Senior Center;
- Two Court-Appointed Guardianship program; and
- The Selfhelp Alzheimer's Resource Program (SHARP).



Throughout the extensive services that Selfhelp provides, many of our programs encounter individuals who provide caregiving services to a family member. Many of these caregivers are adult children who are juggling the responsibilities of caring for an elderly parent, raising their own families and working outside the home to support their families. I imagine that many of you in this room find yourselves in this challenging situation. Others are individuals who are aging themselves and find it increasingly challenging to live with and care for their affected spouses.

Selfhelp's SHARP program is a social adult day program for individuals with Alzheimer's Disease, dementia and other memory impairments. The program provides socialization and stimulation to the individual with the memory impairment while providing the caregiver with a much needed break from their caregiving responsibilities. This allows the caregiver to recharge their batteries so that they can continue to care for their loved one for as long as possible. The SHARP program also provides a caregiver support group where caregivers can come together to share experiences as well as to learn and support each other.

Social adult day care programs provide services to enable individuals to continue living in the community for as long as possible. Caregiver support is a critical aspect of these services.

The New York City Department for the Aging provides funding to eleven caregiver programs throughout the city of New York. The services provided by these programs are invaluable. As residents of New York City continue to live longer, we urge the New York City Council to respond to the increasing needs of this population by increasing the funding for caregiver services.

I thank you for giving us the opportunity to present this testimony.

**New York City Council  
Committee on Aging  
Oversight: Providing Support to New York City's Caregivers**

**December 9, 2014**

Good Morning. My name is Shyvonne Noboa, Director of the Western Queens Caregivers Network of Sunnyside Community Services. I am here to represent the organization and the Network composed of Queens Community House and HANAC.

Support from the Department for the Aging (DFTA) towards Caregivers support is an essential service in our community and today, I call upon you to increase this much needed funding stream.

The program provides services and support that lessen the strain informal family caregivers experience in their roles. We serve approximately 550 individuals each year including those who are the primary caregiver to an individual over age 60, grandparents 55 years and older raising a grandchild, and individuals over the age 60 caring for a disabled adult. We provide individual and group counseling; care giving skills training workshops and psycho educational sessions; assistance in accessing benefits and entitlements; as well as individual and group respite. Our network is able to provide services in English, Spanish, Russian and Greek. Before reaching us, caregivers were burned out, stressed and had reached the breaking point. Our caregivers have repeatedly told us that this program and support services offered were and continue to be life changing.

One such example is Maria whose mother is in the early stages of Alzheimer's Disease. Maria is an only child, with no one to share the responsibility and duties of family caregiving. Maria checks in on her mother daily, shops for her, manages her finances, and advocates on her mother's behalf. She accompanies her mother on all medical appointments. She is a public school teacher and must continue to work. She reached out to us when she realized she needed additional support and was overwhelmed trying to manage her mother's financial situation and daily care. She also realized she needed to plan for the future as the disease progresses. Our caregivers program helped Maria through the complex process to obtain Medicaid Long Term Care, helping her gather necessary documents and complete and submit the applications for Medicaid. We then helped them complete and submit an application for a pooled income trust, to manage the mother's Medicaid surplus and submitted the documents to Medicaid.

Her mother began attending our Social Adult Day program several times a week. Maria's mother is enjoying the program, and is benefiting from the social engagement. Just as important, Maria knows that her mother is in a safe environment while she is at work and can focus her attention there. With our support, they have enrolled in a Managed Long Term Care plan and now receive home care services. The dedicated worker is assisting Maria's mom her daily needs and keep her safe. All of this profoundly changed Maria's life and she now feels she has the resources needed to

continue to care for her mom. This is just one of hundreds of examples I could provide that detail the complexity of these situations and the profound impact these services have on the lives of many.

I would like to take this opportunity to thank you for allowing me to speak to you today and for your continued support of NYC Caregivers and older adults in New York City.

Thank You

Shyvonno Noboa, LMSW  
Director of Western Queens Caregiver Network  
Sunnyside Community Services, Inc.  
43-31 39th Street  
Sunnyside, New York 11104  
Phone: 718.784.6173, ext. 440  
Fax: 347.448.8458  
snoboa@scsny.org

**Blanca Cintron  
23-19 92nd Street  
East Elmhurst, NY 11369**

The New York City Council  
118-35 Queens Blvd, 17th Floor  
Forest Hills, NY 11375

December 5, 2014

Dear City Council Representative Karen Koslowitz,

As an advocate for caregivers for Alzheimer's parents, I would like to stress the fact that caregivers are not taken seriously by most people. Most people you talk to have no idea or clue of what dementia or Alzheimer's is. They say, "It's an old folk disease." They just don't know. This disease not only affects the patient but also their loved ones and everyone around them.

I have been taken care of my mother for approximately ten years since she was getting older and had started getting medical issues. She was diagnosed with degenerative vascular dementia four years ago. It has been a trial-by-fire experience to say the least. Nothing can prepare one for what waits ahead. No matter how much I read, went to classes, seminars at the Alzheimer's Association, research online, visited various doctors, talked to professional regarding Alzheimer's, it was still overwhelming. This has been one of the most difficult times of my life. It felt like I was catapulted into the sky with a free fall to earth, very frightening.

My mom is lucky in the sense that I'm the one planning her life right now. No one else has stepped in to help but I had the opportunity find a support group that has helped me tremendously with planning ahead with Power of Attorney, Health Care Proxy, Living Will, Pre Plan funeral directives and Medicaid paperwork. Just filling out the Medicaid paperwork could make anyone cry. There was many nights that I wasn't able to sleep just thinking about all the things that had to be done and not having enough time to do it all. It's also frustrating when other members of the family do not help; I have seven siblings, but so far I'm the one stuck with this job. I'm hanging in there.

We, caregivers, work hard to keep our parents comfortable, fed, bathed, clothed, exercised, and happy. Make sure that they are medically sound, have all their medications and take all their medicine. I do mostly everything for my mom, who has been diagnosed with Mid Stage dementia. I do her laundry, shopping, bills, letters, phone calls, doctor's appointments. It's been a very tiring, time-consuming, frustrating, and exhausting time but there are moments that can be quite rewarding. There are never enough hours in the day to do all the things that entails taking care of a person with dementia. Most of the time one has to sit and reassure the parent that everything is okay, calm them down because they are so, so lost and confused. I know that my mom finds comfort when I'm around. When I'm not around, for

instance, when I'm working, she's always asking for me. When is Blanca coming home, where is she, what is she doing, etc. So my mom is aware of me now and then. There are moments recently that she forgets who I am, but in her heart, she knows that I'm important to her, because she holds my hand and smiles and ask, "Who are you?" "Are you my mother?" I love my mom and want her to live for as long as possible, but the outcome of Late Stage dementia is frightening. I pray that I'm strong enough to be able to cross that awful bridge. There are many nights that I go to sleep crying and desperate. What is going to happen next?

We as a society must and have to do more to take care of our caregivers. I've been extremely fortunate to belong to a support group that has been valuable to me. They provide help, comfort and a great sounding board. I don't know what I would do without them. They have become my "family" and mean a lot to me. I would be completely lost without them. They are my rock.

I understand that there will be City Council meeting next Tuesday at City Hall, but unfortunately I can't time off during the day. I take enough hours off to take my mother to her medical appointments and for minor emergencies. My boss, thank God, has been very tolerant and I don't want to take advantage of his generosity. Balancing work and taking care of mom sometimes seems like an endless pool going nowhere. There has to be a program for us caregiver's to be able to take time off so we may be able to take care of our loved ones that need us so desperately. I think a program for caregiver's to be able to take a little respite, relax, unwind and just breathe. The motor is slowing down; I'm not the energized bunny that I used to be, even though I tried not to admit that to myself or others.

We caregivers need moral, financial, and mental support. I want to be able to keep my mother in her apartment for as long as possible. With the help of two wonderful help aides, I have been able to keep my mother safe and secure, but I don't know how long that will last. Everyday is a new situation come up that requires tweeting.

To change the direction of this destructive disease, we have to move towards providing better support for all the millions of our constituents who have or are caregivers of people who have this dreadful disease, to find a treatment, prevention and one day a cure.

We are in dire need of your help. Alzheimer's can't wait. Please support us caregivers that do so much for our loved ones.

I thank you for your time in reading this letter (I tend to ramble) and I pray that something can be done to help us.

Respectfully,

Blanca Cintron



**Council of Senior Centers & Services of NYC, Inc.**

49 West 45<sup>th</sup> Street, Seventh Floor, New York, NY 10036 (212) 398-6565 <http://www.cscs-ny.org>

**CITY COUNCIL COMMITTEE ON AGING  
COUNCILWOMAN MARGARET CHIN, CHAIR  
CAREGIVER HEARING  
DECEMBER 9, 2014**

Council of Senior Centers and Services' (CSCS) mission is to champion the rights of older adults to make NYC a better place to live and age. CSCS' 100 member organizations provide community based services through more than 600 programs, serving 300,000 older New Yorkers. CSCS members include multi-service senior centers, meals-on-wheels, case management, elder abuse services, home care, transportation, adult day services, housing, mental health and a broad array of community-based services. CSCS convenes the NYC Family Caregiver Coalition.

CSCS is appreciative that Chair Councilwoman Margaret Chin and the Aging Committee have convened this hearing. Given the broad impact of caregiving and the increasing number and diversity of caregivers and older adults, it is time for the city and state to support the thousands of New Yorkers who are the backbone of holding families together. Families want to care for their older loved ones. ***According to a 2011 AARP report, over four million family caregivers are providing unpaid care for a loved one, contributing an estimated 2.7 billion hours annually at an estimated worth of \$32 billion that the city and state don't have to pay for.*** While caregivers are economically supporting the city and state, they are often struggling themselves financially, physically and emotionally. All they are asking for is some support.

***Caregiving and access to affordable elder care is the workforce issue of the 21<sup>st</sup> century, particularly for women. Older women are also impacted as almost 25% of caregivers in NY State are aged 75 or older. Investing in caregiver support services is supporting in women who are anchors in their families.*** According to the NY State Office for the Aging's 2009 caregiver report, the person most likely to provide care to an older person is a daughter (48%), a wife (23%), a husband (10%) and a son (10%). Often, daughters-in-law are also providing care. National statistics report:

- ✓ The average family caregiver nationally spent \$5,531 per year in out of pocket caregiving – more than 10% of the median income for a family caregiver.
- ✓ This has intensified during the economic downturn – Nearly half report using up all or most of their savings and 43% saying they borrowed money or increased their credit card debt.
- ✓ More than one-third of caregivers, age 50+, reported quitting their job or reducing their work hours in 2007.
- ✓ Informal caregivers personally lose about \$659,139 in earnings and benefits over a lifetime – foregone wages (\$566,443); lost Social Security (\$25,494); lost pension benefits \$67,202).

***This is economically devastating to millions of women in NY and the nation. Caregiving can also be emotionally detrimental and isolating.*** To date, the city and state have turned a blind eye to supporting caregivers. The only funding, \$4 million, for caregiver supports through the Department for the Aging is federal Older Americans Act funding which has remained stagnant for years.

***Imagine the difficulties faced by adult children or spouses caring for their elderly parents, spouse or other loved one if the care recipient isn't eligible for benefits.*** CSCS recommends that the city add funds to the Department for the Aging budget for supportive services for all family caregivers with attention paid to caregivers who may also be immigrants caring for their immigrant parents. The funding is contracted out to service providers that support family caregivers from immigrant communities as well as the LGBT, disabled and other communities. Investing in caregivers is an investment in helping older adults age in place in their communities and women staying in the workforce.

### ***Impact of caregiving on immigrant and diverse communities – national statistics -***

#### **Hispanic Community:**

- ✓ One-third of Hispanic households report having at least one family caregiver.
- ✓ 4 in 10 working Hispanic caregivers report making a major workforce change, such as taking a leave of absence, changing jobs, reducing hours, or stopping work entirely.
- ✓ Most Hispanic caregivers don't know where to go to find services. They turn first to health care professionals, family and friends, and then government agencies.
- ✓ About ¾ feel that information and services delivered in Spanish are important.

#### **Asian Community:**

- ✓ Asian-American caregivers are more likely to care for a relative than caregivers overall (92% to 86%). They are twice as likely to care for a grandparent or grandparent-in-law (18% vs 8%).
- ✓ A large portion of Asian caregivers feel they do not have a choice about caregiving.
- ✓ 50% of Asian caregivers are men.
- ✓ Asian caregivers report higher household incomes than caregivers from other ethnic backgrounds and are more likely to say caregiving is not a financial hardship by rating it one or two in a five point scale.

#### **African-American Community:**

- ✓ African-Americans are more likely to be primary caregivers out of all ethnic/cultural groups (65%).
- ✓ More than half of African-American caregivers find themselves "sandwiched" between caring for an older person and a person younger than 18 or caring for more than one older person.
- ✓ African-American caregivers are more likely to live with the care recipient.
- ✓ 66% of African-American caregivers are employed full or part-time.

#### **LGBT Community:**

- ✓ LGBT caregivers are slightly more likely to have provided care to an adult friend or relative in the past six months than the general population (21% vs. 17%).

### **Recommendations:**

**1. Caregiver support funding - \$3 million –** The only funding available for caregiver support services is through the federal Older Americans Act. NYC needs to allocate funding because providing supportive services for the caregiver herself is key to her wellbeing and of the care recipient. This includes respite care, home care or a temporary placement, to allow the caregiver to take care of things in their life, support groups and other

assistance. Listening to caregivers and what they identify as their needs is key. Connecting the caregiver to other services is also important. Funding should be baselined.

**2. Fund aging services** – Services such as case management, home care, senior centers, social adult day care, home-delivered meals – all provided by the DFTA funded community-based aging services network support family caregivers by providing services for their loved one.

**3. Support state legislation to expand both paid and unpaid family leave and address the need for workplace flexibility** –

Support from City Council and the de Blasio administration to pass state legislation which includes language regarding caregivers for older adults is important. Including such legislation in City Council's and Mayor de Blasio's state legislative agenda would be helpful.

**4. Pre-discharge training for caregivers** – Family caregivers are left on their own to administer medication and provide other complicated and physically difficult care to their loved one upon discharge from a hospital. Legislation to require hospitals to train caregivers is needed. This would also help reduce the mounting costs associated with hospital readmissions.

**5. Access to affordable legal assistance** – Caregivers often need legal assistance related to finance and health. This includes living wills, health care proxies, HIPPA, medical orders for life sustaining treatments, and power of attorney as well as paying for long term care. Without these legal documents in order, caregivers face great complications.

**6. City gathering statistics on caregivers** – New York City should develop an annual document tracking caregivers – who they are, where they live, income, immigrant/diversity, workplace issues, what they need, etc. Without this data, it is not possible for the city to plan for the growing number of caregivers and to make these thousands of mostly women visible. Thousands of women are caregivers today and thousands more will be taking on a caregiver role for the city's fastest demographic – older adults and the 85+ in particular.

**7. Public Education Campaign** to increase awareness of caregiving and the resources available in the City.

Women have been caregivers their whole lives. CSCS would like to work with City Council and the de Blasio administration to develop a plan to address the needs of the backbone of long term care services – family caregivers.





**EmblemHealth®**

55 Water Street, New York, New York 10041-8190

**Gregory Johnson**

Creator: Care for the Family Caregiver Initiative  
Director, Community Outreach  
FELLOW: NY Academy of Medicine  
(646)-447-7651

FEBRUARY 19, 2014

**The American Psychological Association, the International Council of Psychologists,  
the International Federation on Ageing, Global Aging, the NGO Committee on Ageing/NY and  
the NGO Committee on the Family/NY**

invite you to attend a side event for the

**FIFTY-SECOND SESSION OF THE COMMISSION FOR SOCIAL DEVELOPMENT**

**THE UNITED NATIONS, NEW YORK CITY, USA**

---

**Older Persons and Families Count:  
Looking at Empowerment, Decent Work and Poverty Eradication**

Wednesday February 19, 2014 10-11:30 AM

---

**Older Persons Contributions to the Family**

GOOD MORNING (Protocol to be followed.....formal/informal TBA)

My name is Greg Johnson and on behalf of EmblemHealth’s CARE for the FAMILY CAREGIVER initiative I am honored to return to the UN here in NYC and to be part of this panel with my dear friend and mentor, Helen Hamlin and my new friend, Susanne Paul.....

I stated “to return” because over a decade ago EmblemHealth’s CARE for the FAMILY CAREGIVER initiative was privileged to present a live performance of CARING FOR ME; CARING FOR YOU, a

theatrical exploration of family caregiving that launched our family caregiving work/passion.....here at the UN in the lovely Dag Hammarskjold Theatre.....and that play continues to serve in our work. In fact, a newly edited version has been produced and is available for each of you.....

In 2001 I was invited by EmblemHealth to create a program “that would bring attention to the ‘*silent patients*,...the family caregivers, and our focus was to be our employees, our members and the community at large. I am pleased to report that effort continues and has taken me around the world.....talking about family caregiving.....or CARERS as we are known in most of the world.....save the US (after all no New Yorker could ever get 2 “r’s” in one word).

And.....wherever in the world I speak, whether a noted setting like today or the basement senior center of a local church.....I begin the same way.

Today.....if you remember nothing else I have to say.....please know I have come to say the two words family caregivers rarely if ever hear: THANK YOU!.....You are the backbone of the world’s healthcare systems – THANK YOU! THANK YOU!

And we need to remember just what healthcare systems are.....they can best be compared to a three legged stool.....THUS, ALL THREE LEGS ARE OF EQUAL VALUE AND NEED.....

1.....CARE RECIPIENT

2.....PROFESSIONAL CAREGIVER (Paid professional, from doctor to home health aide)

3.....The unpaid family caregiver.....from both family of origin and family of choice.

With this third leg, I want to remind all of us.....that each of us has both a family of origin (our blood line as it were) and many families of choice (our friends, our apartment house in NY and other large cities; faith communities, social groups, senior centers; political groups; support groups....and on and on)

Also.....before I pursue briefly my assigned topic.....I wish to continue to set the stage as it were, or level the playing field with a quote attributed to former First Lady Rosalynn Carter..... ***“There are only four kinds of people in the world: Those who have been caregivers; those who are currently caregivers; those who will be caregivers, and those who will need caregivers.”***

And each of us plays many of these roles, at times simultaneously.

When I was asked to create the EmblemHealth initiative I must admit my focus went at once to my late grandparents.....long dead. But like much of the world when I heard the words “family caregiver,” my mind went to older people, the elderly.

My personal and academic background has been theatre and theology.....I was not trained in the world of healthcare or healthcare policy.....BUT.....and here was my initial interest: As an ordained minister I had buried more caregivers than care recipients. Today, after years of professional study, research, and advocacy, I know that my earliest thoughts about WHY have been confirmed.....and today I devote my life to what I like to call The Spirituality of Family Caregiving.....that which comes prior to policy and program. It is focusing on the essence of family caregiving and finding in it.....THAT WHICH UNITES.....for family caregivers unite the world through what I refer to as



GOLDEN RULE LIVING..... “doing unto others what one day each hopes, prays and believes others will do for them.....that is GOLDEN RULE LIVING.

Now while family caregiving is indeed about SENIORS.....that is only part of the story and it has been in working with seniors and senior communities that we have vastly expanded the: MANY FACES OF FAMILY CAREGIVING.. I will share more as we move on.....

In fact on April 30 here in NYC, YOU ARE ALL INVITED.....to the NY Academy of Medicine, the EmblemHealth NYC Partnership for Family Caregiving Corps in association with Fordham University Graduate School of Social Work will present a FULL DAY SUMMIT on Family Caregiving:

Name It; Know Its Many Faces.....FREE.....TO ALL: medical personnel, social workers, clergy, healthcare ministry leaders, government employees, students and family caregivers.....WE ARE ALL IN THIS TOGETHER.

My assigned TOPIC: Older Persons’ Contributions to the Family.....My immediate reaction was quite frankly.....

They began it; they continued it as the case may be in each family...in each family of origin.

They showed care and began the life journey in caregiving.

They grew in care and in so doing helped all of us to know the many faces of family caregiving.

And unless you think this has no ROI.....LET ME SHARE.....in the US alone, all this FREE FAMILY CAREGIVING is valued at over \$450 billion US DOLLARS.....annually. That is huge.....and in America there are over 65.7 million family caregivers....that is one in three.

We have all heard and are well aware of the increased length of life or life expectancy.....more and more people are living well into their 90s and beyond 100.....and what does that mean? Among other things:

THE AGE OF THE FAMILY CAREGIVER is also INCREASING.....MEANING, seniors are caring for seniors.....persons in their 60s and 70s are caring for those now often referred to as the Old Old.....think of it. That is not just happening in the US, as you are well aware.

In addition.....many seniors.....are caring for children, and even more commonly for grandchildren.....this latter case is called KINSHIP.....a grandparent caring for a grandchild---a person at least two generations away.

NYC is a leader worldwide in this work.....On a recent trip to Singapore, following my address to members of the ASEAN community gathered for a FAMILY CAREGIVING workshop sponsored by the noted Tsao Foundation.....a lovely Indian lady asked me:

“Do you know of a place called the Bronx?”

And I replied.....”Indeed I do.....and you must be a Presbyterian; and you are asking me about the Presbyterian Senior Services Grandparent Family Apartments.....”

“Right on all accounts” was her reply.

You see the work that PSS has done in the last decade in building a 50 unit apartment complex specifically for grandparents raising grandchildren has drawn attention, and is the model for many other such projects throughout the world.....for it specifically addresses the reality of the new family, the changes in family lifestyle.

In fact, if you really want to see an amazing demonstration of the Unity in Family Caregiving...I urge you to view the film: GRANDMOTHER TO GRANDMOTHER; THE BRONX TO TANZANIA.....an account of the trip that 20 PSS grandmothers and grandkids took to Tanzania to visit a group of grandmothers who are raising their grandkids.....no translation was need.....love prevailed; was celebrated.....lives greatly empowered and worlds were expanded in the lives of each.

There are also many older persons who are providing valuable counseling to other caregivers....they are “veterans of family caregiving”.....as I often say, awaiting their next assignment in life.....they have been there and are better at providing help, hope and humor.....to active family caregivers...a huge, immeasurable contribution to both families of origin and families of choice.

Now as I have considered my topic, I have thought of all the words often used to describe what older persons contribute to life and to the family.

We all know these words: perspective; reality that life is really an inside job; experience; appropriate expectations; joy; awareness and acceptance; listening; support of all kinds; growth; discipline; and the list goes on.

Are each of us successful with this every day? Well, for me; I know I fail often. But, I get back up and try again. Beyond, my professional and ministry work, I am a multiple stroke survivor; I am the last of my immediate family still alive.....my son died at age 40 at my home in Indonesia in 2005 and my partner of 41 years died in my arms in 2011. Life happens.....and each of you could share your journey.....and yet, as we well know, it is NOT WHAT HAPPENS TO US THAT REALLY COUNTS; it is how we grow through it.....and for me the one word on which I wish to focus my final remarks is WISDOM.....

Wisdom.....that grace of INTELLIGENCE AND LOVE united.....in many theological traditions and philosophical discussions.....WISDOM is often defined and portrayed as the combination of INTELLIGENCE AND LOVE.....

The intelligence is that thing called life, life experience, “*growing through the going through*”.

By this many older people contribute to others throughout their lives.....not by giving a sermon; but by being one.

As I often say: ‘With family caregiving you cannot pay it away; pray it away; or prescribe it away.....YOU NEED ALL THREE; but ultimately you need to go through it, and it is my prayer and

our mission to help people GROW through it”.....helping people to know THEY ARE NOT ALONE.  
There is help.....always.

And many times that HELP.....does not appear until we surrender.....until we, and I love this  
definition of surrender: Until we “ let go absolutely; to receive abundantly”

Older persons understand this. They have lived it. They have experienced life; they have experienced  
death, and in that finitude have found the gift of life.....with all its burdens, challenges, difficulties, and  
strife.

They have decided to stop living in the problem; and live in the solution.....those are family caregivers.  
They live in the present.....not the past; nor the future. There is more than enough to do  
presently; to mix the past and future takes much too much energy and wastes resources needed to serve  
others.

Is this intelligence gathering easy.....OF COURSE NOT.....we all know that. Yet, as we look at  
older persons we find, like all persons.....the challenges of life continue and continue. They may  
change in focus....they may change in priority, in their importance to us.....but challenges remain. WE  
ARE ALIVE. There is more to learn on this earthly journey.....

Older persons have learned that life is sharing, caring, changing, challenging, reaching out.....and by  
example, helping others to do the same. Older persons understand that life is MIND—BODY—SPIRIT;  
and in each area we need to continually move forward. They understand the joy and serenity that comes  
from “wanting what they have” rather than “having what they want.”

Now as we gather this “intelligence” the results may vary.....indeed they do; the conclusions can be  
vastly varied.....but in the searching often comes that precious second substance.....LOVE  
which, when combined with Intelligence, produces WISDOM.....

And in finding Love.....each of us gives to the world that which was given to us in the first place.

With love we erase barriers, differences, prejudices and all other forms of divisions.....and we find  
PEACE.....realizing that Peace is not the absence of conflict.....but rather the individual journey  
within to the Source of all being, however you may understand that.....and as each person finds

that peace within.....so we give it to the world.....to the one race to which we all  
belong.....THE HUMAN RACE.....and together, as we become the older people of whom we  
have been speaking.....we contribute through our wisdom to a world in which all persons care for one  
another.....a world that LIVES THE GOLDEN RULE.....just as family caregivers do each  
day.....”doing unto others.....as they wish others to do unto them”.....And it is so

Thank you.....



**FOR RESOURCES/INFORMATION/TOOLS:**

<http://www.emblemhealth.com/familycaregiver> or  
[www.emblemhealth.com/careforthefamilycaregiver](http://www.emblemhealth.com/careforthefamilycaregiver)  
<http://www.facebook.com/careforthefamilycaregiver>  
email: [cffcq@emblemhealth.com](mailto:cffcq@emblemhealth.com)

**TO CONTACT: Gregory L. Johnson; M.Div SMM**

Gregory L. Johnson  
Director, Community Outreach  
Creator: EmblemHealth's Care for the Family Caregiver  
Program  
Marketing and Communications  
FELLOW: NY Academy of Medicine  
EmblemHealth  
55 Water Street; Suite 3B-11  
NY, NY 10041-8190  
1-646-447-7651  
[gjohnson@emblemhealth.com](mailto:gjohnson@emblemhealth.com)



# EMBLEMHEALTH: NEW YORK'S HEALTH AND WELLNESS COMPANY

For more than 75 years, EmblemHealth has been putting care first — for our members and the communities we serve. We are innovators in developing new programs and resources that result in improved care coordination, better health outcomes, higher member satisfaction and lower health care costs.

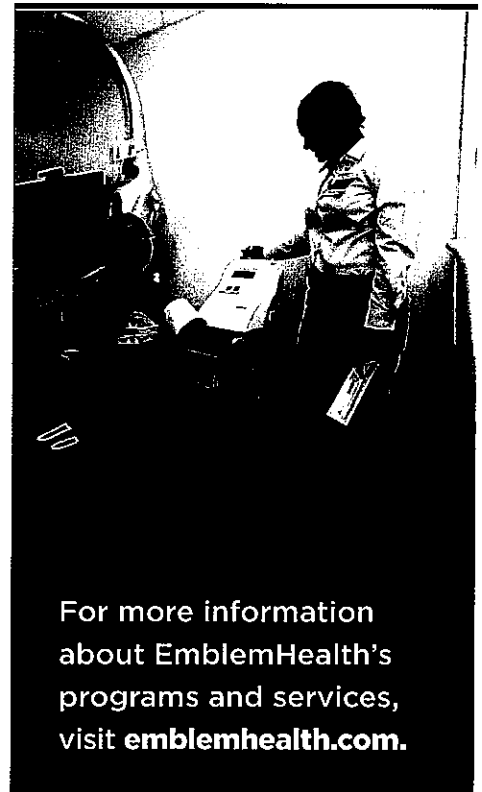
EmblemHealth was created by the affiliation of two companies, Group Health Insurance (GHI) and Health Insurance Plan of Greater New York (HIP), which shared rich histories, local roots and complementary strengths. Then, as now, our mission is to provide affordable, sustainable, high-quality health coverage in ways that respect and respond to people's fundamental needs.

As a customer-focused company, EmblemHealth is committed to providing access to quality care and value to approximately 3.4 million people. By measuring, monitoring and improving the clinical care our members receive, we provide programs, tools and resources to help them stay healthy, get well and live better.

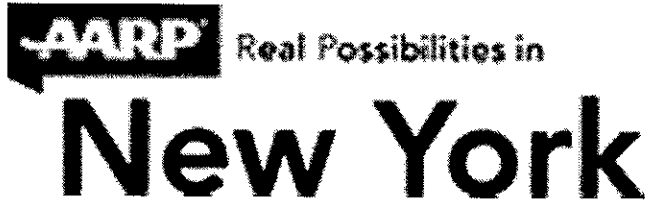
EmblemHealth has been recognized as an accredited health plan by NCGA and URAC. This demonstrates the company's commitment to being an insurer of choice and ensures that members are receiving the best care possible. Honors from URAC and the New York Department of Health confirm that our focus is on continuous quality improvement.

EmblemHealth has always been an integral part of the New York community. We've built on that foundation by increasing our presence in the neighborhoods we serve and engaging with our members where they live. In Harlem, Cambria Heights, Queens, Chinatown and Hudson Guild in Chelsea, members and local residents can meet with a health care expert at EmblemHealth Neighborhood Care to ask questions, get reliable information and have problems solved. To address the growing community of individuals who provide unpaid care to their loved ones, the Care for the Family Caregiver program provides information, resources and support that caregivers need to avoid becoming care recipients. EmblemHealth also partners with a number of local organizations to promote the health and well-being of New York's diverse neighborhoods and to make them a better place to live.

By putting care first, EmblemHealth is achieving quality, sustainable health care. That is and always has been our mission because EmblemHealth is more than just a health insurer — we are New York's health and wellness company.



For more information  
about EmblemHealth's  
programs and services,  
visit [emblemhealth.com](http://emblemhealth.com).



**Testimony of James Arnold, AARP NY Executive Council Member, to  
NYC Council Committee on Aging, Public Hearing, 12/9/2014**

Chairwoman Chin and members of the Aging Committee, Good Morning, my name is James Arnold and I serve on the Executive Council of AARP New York. On behalf of our State Director, Beth Finkel, and our nearly 750,000 members age 50 and older in New York City, I want to thank you for the opportunity to talk about an important but often under-recognized segment of our city, our state and our nation: family caregivers.

They provide care in our homes and our communities to aging parents, spouses and loved ones, and in doing so they make up the backbone of our long term care system. AARP surveyed city voters 50 and older last year and found 47% of those age 50 to 64 and working – and about four of every 10 of all voters 50 and over – are or have been family caregivers in the past five years. That's over 1.1 million people.

More than half of the survey's respondents expect caregiving responsibilities to fall on them in the next five years. That's over 1.5 million people.

And caregiving takes a toll. Two thirds of working caregivers said their caregiving responsibilities caused "overwhelming" or a "good deal" of strain on their and their family's quality of life, including financial hardship, emotional stress and stress at work.

And four of every five of all the survey respondents – caregivers and non-caregivers alike - said strengthening laws and regulations and funding services that support family caregivers should be the "top" or a "high" priority for the city's elected officials.



AARP estimates that across New York state, more than 4.1 million people at any given time provide care that would cost over \$32 billion a year if it had to be paid for.

The New York State Office for Aging (SOFA) estimates that more than 80% of all long-term care is provided by family members, friends and neighbors.

According to a 2009 SOFA survey, "*Sustaining Informal Caregivers; New York State Caregiver Support Programs Participants Survey*," without the services of state programs supporting family caregivers, many caregivers would be forced to place their loved ones in institutional settings like nursing homes that are funded largely by taxpayers through the Medicaid program.

AARP believes it is critical not only to sustain these programs but to strengthen them. As the Baby Boom Generation ages and the number of younger people proportionately decreases, more of us will need care, but there will be fewer family caregivers to provide it. 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 just 4.8 in 2030, and only 3.5 in 2050.

Family caregivers in the city, as in the nation, tend to be working women. SOFA has identified the typical caregiver in New York as a 64-year-old woman who has either high school or some college education and spends more than 40 hours a week providing care to her mother. 85% of the care receivers 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.

Lack of adequate support for caregivers can be costly not only to families and taxpayers, but to employers. A 2006 MetLife study found that nationally, businesses lose as much as \$33.6 billion annually in worker productivity because of employees' caregiving obligations.

Helping family caregivers is an economic imperative, but it's also compassionate. AARP has found that 86 percent of Americans want to remain in their own homes and communities as they age.

But AARP hasn't just studied the numbers. Over the summer of 2013, we joined with the Council of Senior Centers and Services of New York City, Inc. (CSCS), the New York State Caregiving and Respite Coalition and other organizations to hold 12 listening sessions across the state, including one each in Brooklyn and Manhattan, and hear directly from caregivers and service providers.

More than 900 people, all with direct experience in caregiving, attended the sessions, and nearly 500 more responded to an online survey. The vast majority of them agreed that ensuring access to the kind of non-Medicaid, in-home services for the elderly that help give family caregivers help and a break is critical.

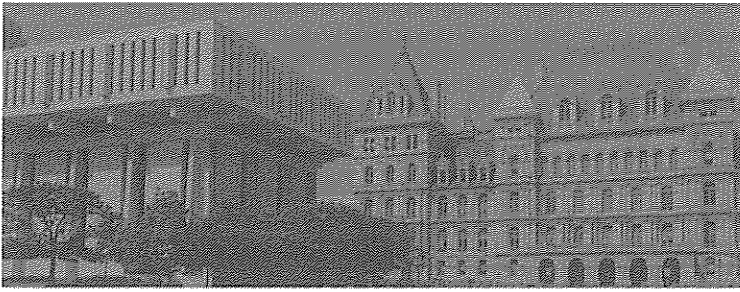
Among the effective programs AARP believes need to be strengthened are the Expanded In-Home Services for the Elderly Program (EISEP), Respite, Meals on Wheels, the Supplemental Nutrition Assistance Program (SNAP), Transportation Services, including to transportation to medical appointments, and the Social Model Adult Day Care Program. These should all receive more funding so any waiting lists are eliminated and any family caregivers and frail elderly who need this type of cost-effective assistance can receive it – before it's too late.

AARP would like to recognize and thank the Council and Mayor Bill de Blasio for the Earned Sick Time law. By increasing the number of businesses that will be required to offer paid sick leave and expanding the definition of "family member" to include grandparents, grandchildren and siblings, more people will be able to attend to their family without worrying about missing pay or losing their jobs.

AARP is joining CSCS to urge your support for allocating \$3 million in funding for caregiver support services and programs through the federal Older Americans Act. We also ask your and the mayor's support for state legislation to expand both paid and unpaid family leave to family caregivers. And AARP strongly supports the "CARE Act," a bill in the state legislature that would ensure family caregivers are not only included in medical records but are provided live care demonstrations, prior to hospital discharge, by hospital staff to make sure they can adequately and properly administer medications, dress wounds and provide care to their loved ones at home – preventing costly hospital re-admissions in the process. Lastly, AARP supports CSCS's request that the City formally track data on caregivers to help you properly plan for their growing numbers.

All of these efforts would support and sustain family caregivers, saving taxpayers money, preserving productivity in the workplace and allowing our parents, spouses and loved ones to age where they want: right at home.

Thank you.



# CAREGIVERS IN CRISIS: Why New York Must Act

February 2014



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.



# Executive Summary

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 well-being 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 types of services and system supports they need.

More than 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.





You try to help. You try to find the resources that can help. But there are so many barriers!  
—John, Rochester

## 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.

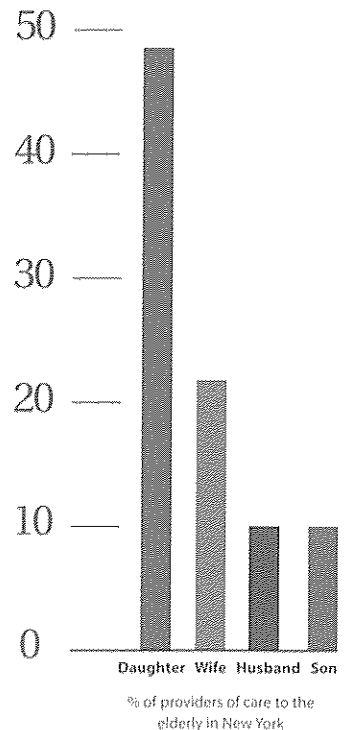
According to the New York State Office for the Aging (SOFA) in *Sustaining Informal Caregivers New York State Caregiver Support Programs Participants Survey* (2009), the person most likely to be providing care to an older person is a daughter (48%), followed by a wife (23%), a husband (10%), and a son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

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.

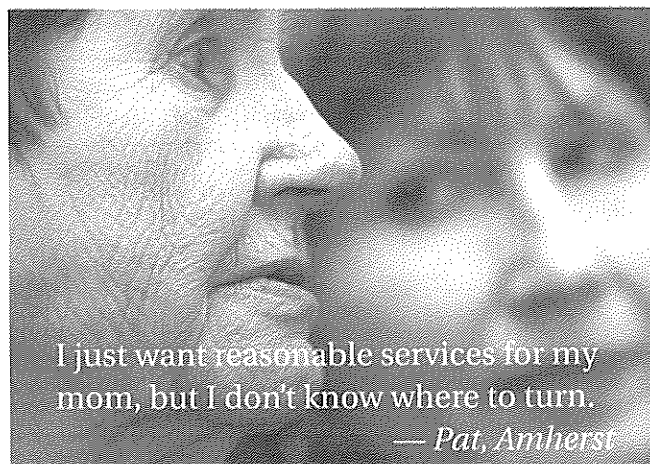
New York State policy on long-term care since Andrew Cuomo became governor in 2011 has been largely focused on slowing the growth of Medicaid. The Medicaid Redesign Team (MRT) process reformed New York's Medicaid program through the institution of a managed care model for the delivery of Medicaid services, 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 New York State 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.

The **60+**  
group increased by  
**15%**  
statewide between  
2000 and 2010.

- **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 2014-2015 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 injections, 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](http://www.sharethecare.org)), Time Dollars ([www.timebanks.org](http://www.timebanks.org)), Mercy Care of the Adirondacks ([www.adkmercy.org](http://www.adkmercy.org)), Hearts and Hands: Faith in Action ([www.hnhcares.org](http://www.hnhcares.org)), Care Links ([www.chsny.org/carelinks](http://www.chsny.org/carelinks)), SAGECAP ([www.sagecap.usa.org/programs/sagecap.cfm](http://www.sagecap.usa.org/programs/sagecap.cfm)), and Faith in Action ([www.putyourfaithinaction.org](http://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):

- |                                       |  |  |
|---------------------------------------|--|--|
| <input type="checkbox"/> bathing      | <input type="checkbox"/> meals                   | <input type="checkbox"/> social activities |
| <input type="checkbox"/> dressing     | <input type="checkbox"/> medical care management | <input type="checkbox"/> transportation    |
| <input type="checkbox"/> housekeeping | <input type="checkbox"/> medication management   | <input type="checkbox"/> other             |
| <input type="checkbox"/> housing      | <input type="checkbox"/> personal finances       |  |
| <input type="checkbox"/> information  | <input type="checkbox"/> respite                 |  |

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

1-866-227-7442

[www.aarp.org/NY](http://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](http://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

### **ACKNOWLEDGEMENTS:**

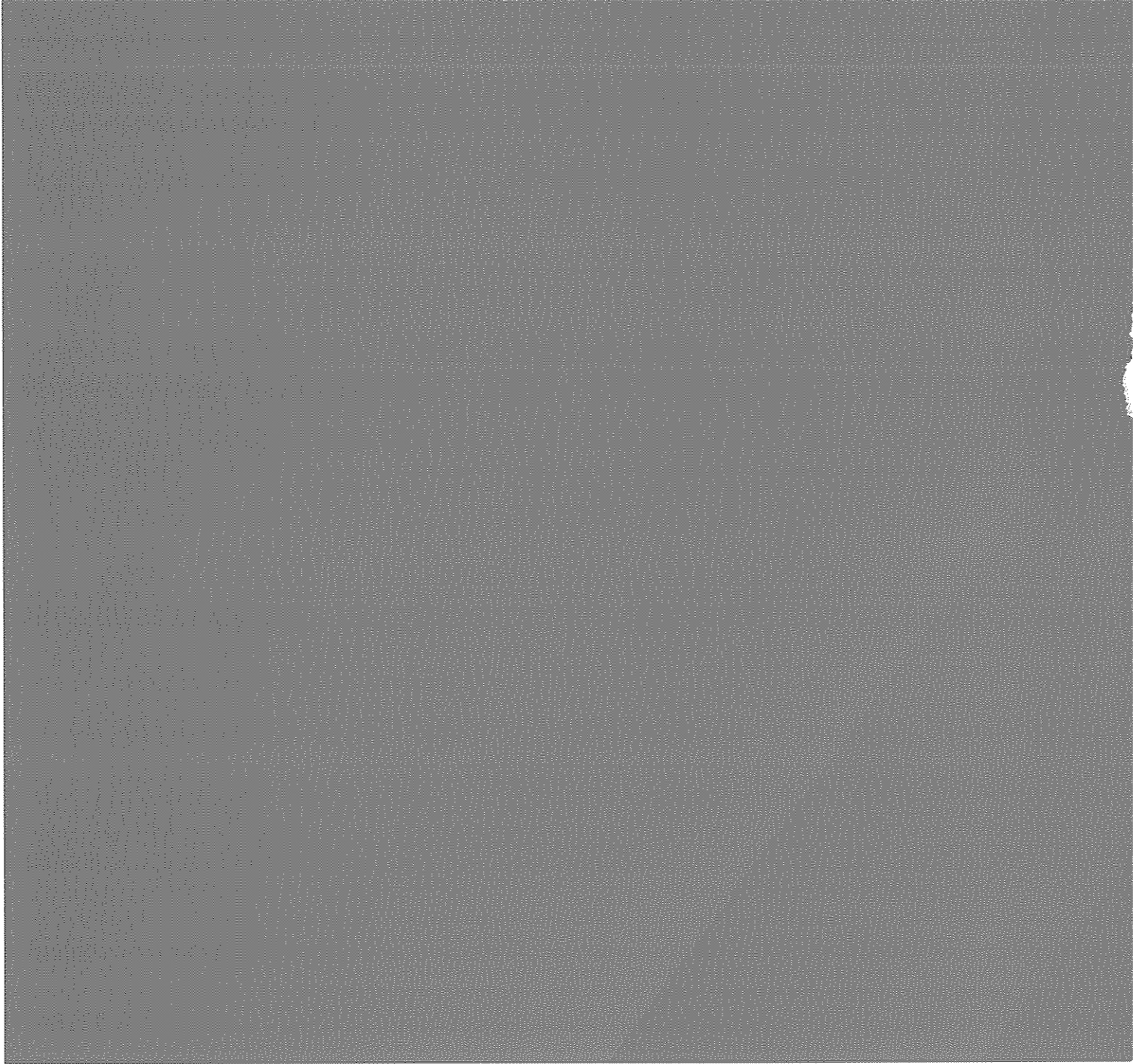
AARP New York, the Council of Senior Centers and Services of New York City, and the New York State Caregiving and Respite Coalition thank Gail Koser for writing this report. We would also like to acknowledge the leadership of Anne Marie Cook, Bill Ferris, Shaun Flynn, Beth Finkel, Ilene Henshaw, Igal Jellinek, Neal Lane, David McNally, Allison Nickerson, Laura Palmer, Enzo Pastore, Susan Reinhard, and Bobbie Sackman, whose dedication to family caregivers and vision for collaborative solutions brought this report to fruition.

We would like to thank the caregivers who shared their experiences so generously with us, both in person and online. We hope that the recommendations in Caregivers in Crisis will be the catalyst that New York State needs to address the enormous challenges that you face in caring for your loved ones.

Finally, we are grateful to the panelists who participated in the listening sessions and made sure that the voice of the family caregiver was heard.

### **Panelists**

Lisa Alford, Onondaga County Aging and Youth  
Julie Allen Aldrich, Monroe County Office for the Aging  
Patricia Butts, Abyssinian Baptist Church  
Suleika Cabrera Drinane, Institute for the Puerto Rican/Hispanic Elderly, Inc.  
Robin Fenley, NYC Department for the Aging  
Sundra L. Franklin, Prime Time Ministry at Emmanuel Baptist Church  
Rhonda Frederick, People, Inc.  
Larry Gile, SAGE  
Keith Harrington, Alzheimer's Association  
Kelly Harris, Alzheimer's Association  
Randy Hoak, Erie County Senior Services  
Rick Ianello, Albany Guardian Society  
Assemblyman Mark C. Johns, New York State Assembly District 135  
Carol Levine, Director, Families & Health Care Project of the United Hospital Fund  
Mary Ann Malack-Ragona, Alzheimer's Disease Resource Center  
Karol Markosky, CSCS of New York City  
Phil McCallion, School of Social Welfare Director at SUNY Albany  
Vicky Meyerhoefer, Nassau County Office for the Aging  
Assemblywoman Joan Millman, New York State Assembly District 52  
Assemblyman Joseph D. Morelle, New York State Assembly District 136  
Gretchen Moore-Simmons, Alzheimer's Association of Northeastern NY  
Congressman Tom Reed, Congressional District 23  
Holly Rhodes-Teague, Suffolk County Office for the Aging  
Christie Sabo, Warren/Hamilton Counties Office for the Aging  
Kim Salisbury, Chemung County Department of Aging and Long Term Care  
Judy Willig, Heights and Hills





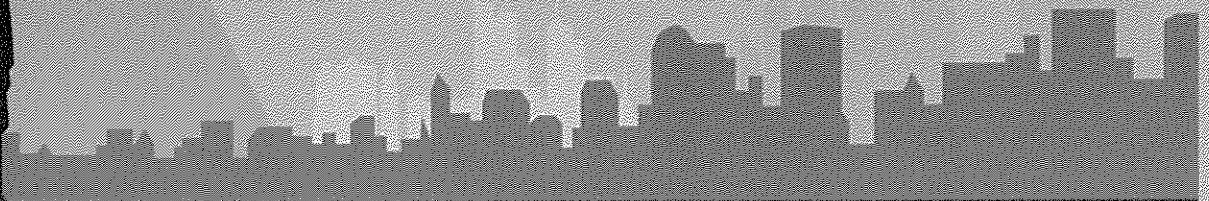
Real Possibilities

# STATE OF THE 50+

in

# NEW YORK CITY

July 2014



# ACKNOWLEDGEMENTS

This report was made possible with the valuable contributions of many people across AARP.

Contributors include:

AARP Research Center Staff: Angela Houghton, Kate Bridges, Cassandra Cantave, Brittne Nelson, Cheryl Barnes, Erin Pinkus, Darlene Matthews, Rachelle Cummins, Sibora Gjecovi, Ed Evans, Joanne Binette

AARP New York: Beth Finkel, David Irwin, Chris Widelo, David McNally, Bill Ferris, Suzanne Towns, Erik Kriss and everyone in the AARP-NY offices

Additional AARP Staff: Jodi Sakol, Steve Griffin, Khelan Bhatia, Pete Jeffries, Coralette Hannon, Enzo Pastore, Gerri Madrid Davis, Mike Schuster, Doris Gilliam

Special thanks to each of the following for their insights, consultation and advice in the production of this report and the associated research:

Susan Reinhard, Senior Vice President, AARP Public Policy Institute

Carlos Alberto Pessoa de Figueiredo, Senior Methods Advisor, AARP Public Policy Institute

Ruth Finkelstein, Senior Vice President, Policy and Planning, New York Academy of Medicine

Joyce Moy, Executive Director, Asian American / Asian Research Institute City University of New York

Luis A. Miranda, Jr., Founding Partner, MirRam Group, L.L.C.

Lorraine Cortez Vasquez, Executive Vice President, Multicultural Markets and Engagement, AARP

## About AARP

AARP is a nonprofit, nonpartisan organization, with a membership of nearly 38 million, that helps people turn their goals and dreams into real possibilities, strengthens communities and fights for the issues that matter most to families such as healthcare, employment and income security, retirement planning, affordable utilities and protection from financial abuse. We advocate for individuals in the marketplace by selecting products and services of high quality and value to carry the AARP name as well as help our members obtain discounts on a wide range of products, travel, and services. A trusted source for lifestyle tips, news and educational information, AARP produces AARP The Magazine, the world's largest circulation magazine; AARP Bulletin; [www.aarp.org](http://www.aarp.org); AARP TV & Radio; AARP Books; and AARP en Español, a Spanish-language website addressing the interests and needs of Hispanics. AARP does not endorse candidates for public office or make contributions to political campaigns or candidates. The AARP Foundation is an affiliated charity that provides security, protection, and empowerment to older persons in need with support from thousands of volunteers, donors, and sponsors. AARP has staffed offices in all 50 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Learn more at [www.aarp.org](http://www.aarp.org).

# TABLE OF CONTENTS

INTRODUCTION	4
EXECUTIVE SUMMARY	6
SECTION I: NYC 50+ Voters	9
SECTION II: Population & Demography	17
SECTION III: Jobs & Work	27
SECTION IV: Economic Security	36
SECTION V: Healthcare	49
SECTION VI: Livable Community	58
APPENDIX:	64
A. AARP Voter Survey Methodology	
B. Annotated questionnaire	

# INTRODUCTION



July, 2014

AARP is proud to present the *State of the 50+ in New York City*. As a leading advocate for the 50+ population, with almost 750,000 members in New York City and over 2.6 million members across the state, AARP is committed to ensuring that all New Yorkers are able to live their best lives as they age. This report takes a deeper, research-based look at this key segment, the increasing population growth and the challenges and opportunities facing them.

New York City has over 8.3 million people of diverse backgrounds, experiences, ethnicities, families, incomes and ages. Within this population, the 50+ are a powerful voting demographic; in fact, 50+ voters were the biggest single voting bloc in the 2013 New York City Mayoral Election.

The age group contributes billions of dollars a year to the local economy, yet from age discrimination to affordability and the reality of being unable to retire; they are facing a unique set of challenges. Many are struggling. As a result, when the majority of Baby Boomers who can retire do, they say they will likely take their pensions, retirement savings and Social Security checks somewhere else – taking about \$50 billion in annual economic contributions with them.

In 2014, the last of the Baby Boomers will turn 50, representing a massive demographic shift. Thirty-one percent, or about 2.6 million, of all New York City residents are 50 years of age or older, 13% are 65 or older, and the 65+ population is expected to rise to 16% by 2030.

As this population booms, how will policy-makers, communities and providers adjust to their needs and talents? We hope the data presented will inform the work of elected officials, community leaders, partner organizations and citizens to help New York City meet the needs and leverage the resources of the 50+ population.

Sincerely,

Beth Finkel  
State Director  
AARP in New York State

# ABOUT THIS REPORT

Various data sources were used in the creation of this report and are referenced within each section. Both population and registered voter-based data are included. All data represents New York City and persons aged 50 and older unless otherwise noted.

In addition to various secondary and previously published survey data, a key source of primary data in this report is a telephone survey of n=1,302 registered voters age 50 and older living in the five boroughs of New York City, with an oversample of n=300 Asians. The sample also included representation of 50+ Hispanics and African American/Black voter groups in NYC. The survey of voters was fielded in June 2013 and interviewing was conducted in English, Spanish, Chinese (Cantonese and Mandarin), Tagalog, Korean and Hindi. Additional details on the survey methodology are included in the Appendix of this report.



For clarity, charts representing survey data among registered voters is called out with this symbol.

Throughout the report, tables and graphs may not sum to 100% due to rounding or omission of categories with very small percentages.

The terms “Boomer” and “Senior” have been used in this report to refer to mutually exclusive age cohorts in the population for purposes of comparing and contrasting subgroups of the 50+ population. In this report, “Boomers” refers to those aged 50-64 and “Seniors” refers to age 65 and older.



# EXECUTIVE SUMMARY

This report is based on multiple data sources and examines demographics, published statistics and opinion polls to provide an overall picture of New York City's population aged 50 and older. We present evidence of the power of 50+ voters and information related to the needs of NYC's older population on the dimensions of home, work, economic security, healthcare and age-friendly living.

The big backdrop to this story is the significant demographic shift toward an aging population that is in our midst - globally, nationally and also in New York City. According to the Organization for Economic Cooperation and Development (OECD), life expectancy in the U.S. increased by 8 years from 1970 to 2011 when it reached 78.7 years. All across the U.S., the combination of increased life expectancy and an aging baby boom generation is driving a very fast growing 65+ population. Based on an AARP analysis of Census data, over 500 New York State residents are expected to turn 65 every day in the coming years. Over the next two decades, the share of people living in New York City who are aged 65 and over will change from one in eight, to one in every six residents. This population shift is bringing with it opportunities and challenges of a "longevity society" that will impact the economy, public policy, our communities, families and individuals.

Some issues of importance for older New Yorkers highlighted in this report are not so new - for example, family caregiving and retirement security - but they are newly reaching critical mass such that they require attention from policy makers and legislators. Other dynamics affecting this population are relatively more contemporary such as workforce changes; identity theft and fraud threats to economic security; and a shift in family and household compositions from predominantly married couples toward more single and multigenerational households.

Some of the key takeaways in this report include:

## **POWER OF 50+ VOTERS**

- 50+ New Yorkers are a uber voting bloc. Although voter turnout in NYC is low overall, 50+ voters are over represented at the polls relative to their share of the City's voting age population (54% of voters last November and 37% of the 18+ population).

# EXECUTIVE SUMMARY

## PEOPLE & FAMILIES

- Like NYC's total population, there is no single majority race or ethnic group among the 50+. Half of the 50+ were born outside of the US and 15% live in English-isolated households. The 50-64 year old cohort is even more diverse than the 65+, which will require an ongoing and increasing attention to cultural relevance to meet the needs of the overall 50+ population in the coming decades.
- Older women are more likely than men to live either alone or without a spouse. Fewer than half of 50+ households in NYC are occupied by married couples and a full third are headed by unmarried females. At ages 65 and older, households are more than twice as likely to be occupied by a woman living alone (22%) than a man living alone (9%).

## JOBS & WORK

- On average, older adults are working longer than before and feeling anxious about their financial security. Half of 50+ NYC voters in the workforce are not confident they will ever be able to retire or be able to live comfortably in retirement. At the same time, large numbers are experiencing or observing discrimination against older workers. Seven out of ten 50+ NYC voters are concerned about age discrimination.

## ECONOMIC SECURITY

- Despite individual feelings of financial insecurity, as a collective, 50+ residents in NYC represented more than \$70BN in consumer spending in 2011. With 53% of all Boomer-aged (50-64) New Yorkers saying they are likely to leave NYC as they retire and age, at stake is a significant loss to the City's economy if they flee and take their buying power with them.
- Ensuring affordable housing, including the cost of utilities, is a critical aspect of safeguarding economic security for the City's older residents. More than half of 50+ NYC voters (54%) say a lack of affordable housing is a major problem where they live. Nearly six in ten are extremely to very concerned about paying rent and almost half are concerned about being able to pay for utilities in the coming year.

# EXECUTIVE SUMMARY

- Widespread worry among NYC 50+ about protecting current assets from consumer fraud and identity theft, combined with high levels of poverty and hunger among NYC Seniors (65+), also contribute to making many 50+ voters feel vulnerable and financially insecure.

## HEALTHCARE, CAREGIVING & AGING AT HOME

- Concerns about affordable healthcare and gaps in accessing affordable long term care services put increasing responsibility on family caregivers to help their loved ones and honor preferences to “age in place” at home and in their community.
- NYC 50+ voters want their elected officials to promote age-friendly living in their communities, meaning access to alternative transportation, pedestrian safety, and affordable services to enable independent living.

50+ voters in New York City are an engaged voting constituency. Many of the issues important to them relate to so-called “kitchen table economics”, which affect their everyday lives such as employment, caregiving and fraud threats. It is our hope that the data and findings here will be useful for NYC policy makers, community based organizations and elected officials to strengthen the City as a place for its 50+ residents to live and thrive in a longevity society.

# I. NYC 50+ VOTERS

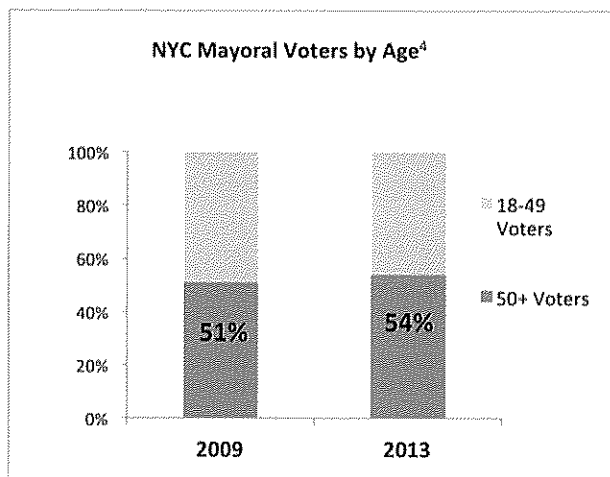
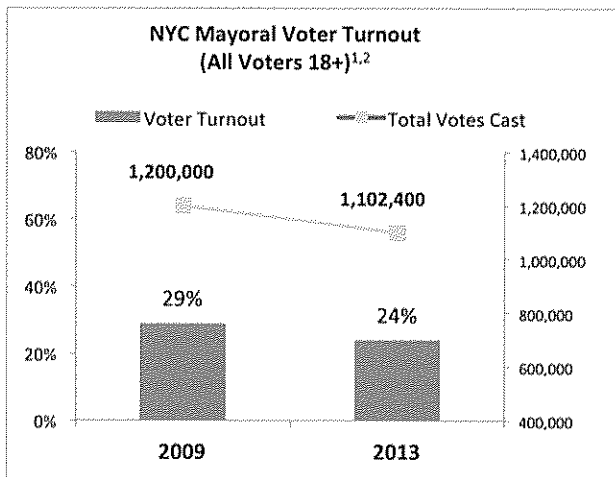
- The Most Powerful Voting Bloc in NYC
- What's on Their Minds?

# PERSISTENTLY LOW VOTER TURNOUT OVERALL IN NYC AND RELATIVELY HIGH PARTICIPATION FROM OLDER VOTERS RESULTS IN A POWERFUL 50+ VOTING BLOCK

According to a 2012 report by the NYC Campaign Finance Board, "Who Votes? Voter Turnout in New York City", voter turnout in the City has been historically low with significantly lower participation rates compared to the rest of the state and the nation. Even compared to other large urban areas, a smaller proportion of registered voters cast ballots in NYC in both the 2008 presidential and the 2010 Congressional elections. <sup>1</sup>

In 2013, New York City again saw low voter turnout for citywide elections of several major offices including mayor, City Council, borough presidents and comptroller. The election was the first time in 12 years there was no incumbent running for mayor and despite the large number of items on the ballot, just one-fourth (24%) of registered voters cast votes<sup>2</sup> - a decrease from the 29% turnout rate in 2009.<sup>1,2</sup> Yet, the share of the electorate represented by 50+ voters increased slightly compared to 4 years prior - from 51% to 54%. Of the 1.1 million ballots cast for NYC mayor in 2013, about 584,000 came from a 50+ voter.<sup>3,4</sup>

State of the 50+ in NYC 2014



At 54% of the electorate, the 50+ represent a significantly larger share of voters than their 39% of the total voting age population (18+) in NYC.<sup>5</sup> In its analysis of NYC voter turnout, the NYC Campaign Finance Board also concluded that adults under age 30 are less likely to vote than older adults.<sup>1</sup> As a result, the interests and needs of New Yorkers age 50 and older will drive results at the polls.

**IN THE 2013 NYC MAYORAL ELECTION, 50+ VOTERS ACCOUNTED FOR MORE THAN HALF OF ALL BALLOTS CAST <sup>3</sup>**

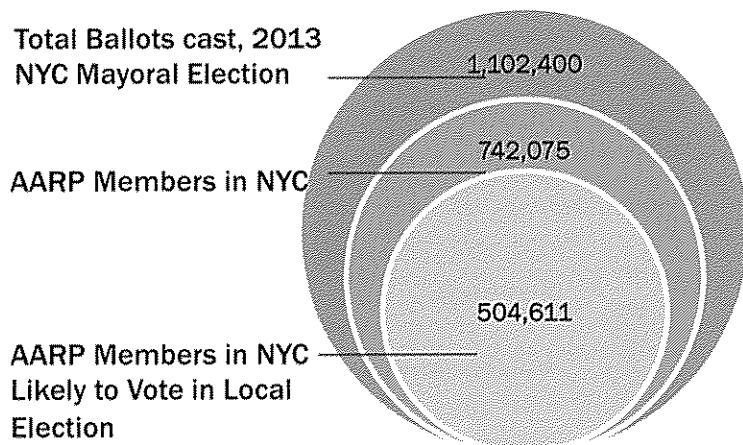
## AARP MEMBERS REPRESENT AN UBER VOTER GROUP WITHIN THE 50+ COHORT IN NYC

In addition to age and other demographic and socio-economic factors that are predictive of voter participation, the NYC Campaign Finance Board also recognizes a positive relationship between group membership and voter engagement, noting that groups, such as unions, mobilize their members to participate in and influence the electoral process.<sup>1</sup>

AARP is a non-partisan membership organization with more than 740,000 members in NYC. AARP engages its members and the general public on key issues of importance for the 50+ by providing information, holding debates and sponsoring grassroots activities. It does not endorse candidates, have a PAC, or give money to campaigns or political parties.

In a 2012 survey of its members, 68% of AARP members in NYC - or more than 500,000 New Yorkers - said they vote in local or state elections.<sup>6</sup> This could represent as much as 86% of the 584,000 votes cast by a 50+ voter or 46% of all votes cast for mayor in 2013.

### Potential AARP Member Representation in 2013 NYC Mayoral Electorate

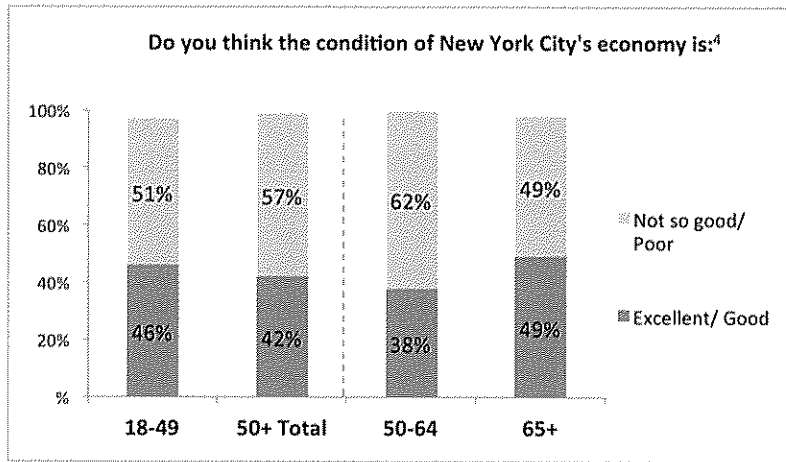


**AARP MEMBERS REPRESENT A SIGNIFICANT PROPORTION OF NYC VOTERS PARTICIPATING IN LOCAL ELECTIONS**

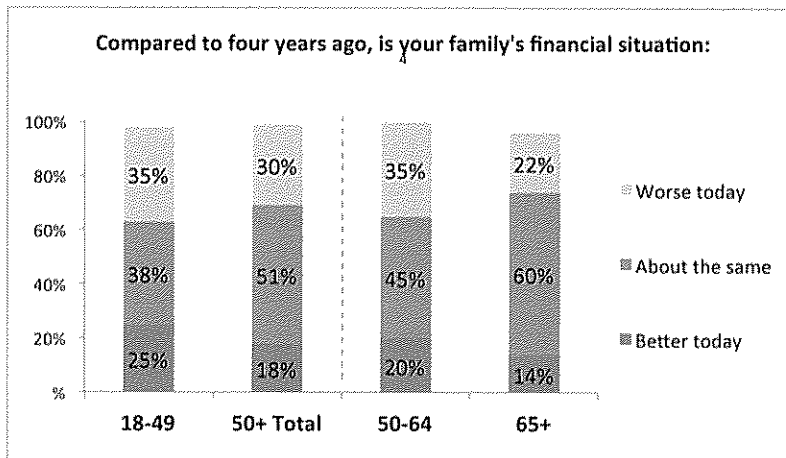
# ECONOMIC ISSUES WERE ON THE MINDS OF 50-64 YEAR OLDS ON VOTING DAY

## SIXTY PERCENT OF BOOMER VOTERS SAID NYC'S ECONOMY IS "NOT GOOD" AND ONE-THIRD ARE WORSE OFF VERSUS FOUR YEARS AGO

According to exit polls conducted by Edison Research on the day of 2013 citywide elections, Boomer aged voters (50-64) who cast their vote mostly had negative opinions about NYC's economy. Voters in this so-called "sandwich generation" were more likely than older or younger voters to view NYC's economy as poor or not so good (62% age 50-64; 49% age 65+; and 51% age 18-49.)<sup>4</sup>



Although the majority of voters overall indicated their family's financial situation either improved or stayed the same since the last mayoral election year in 2009, a full third (35%) of 50-64 year olds feel their situation is worse today than four years ago. Although an equal percentage of 18-49 year old voters reported being worse today, there is also a slightly larger proportion in the younger cohort who feel better today (25% vs. 20%).



Comparatively, Senior voters (65+) were most likely to report a status quo financial situation for their families with 60% "about the same" as four years ago.<sup>4</sup>

24%

ONLY ONE-FOURTH OF NYC REGISTERED VOTERS  
CAST A BALLOT FOR MAYOR IN 2013

-12-

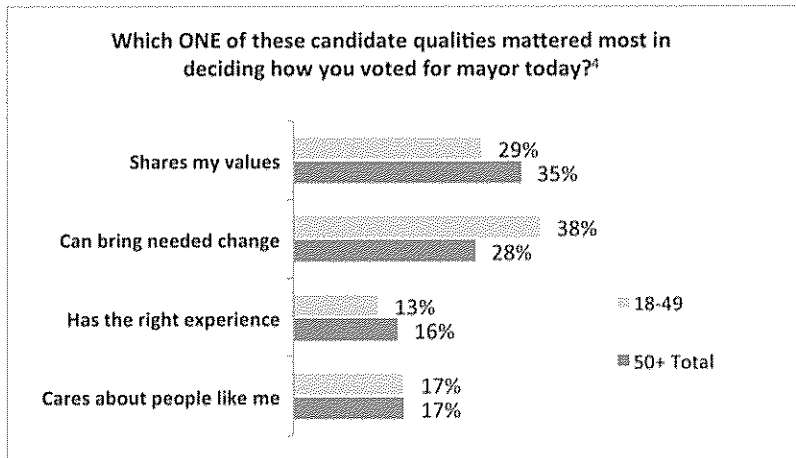
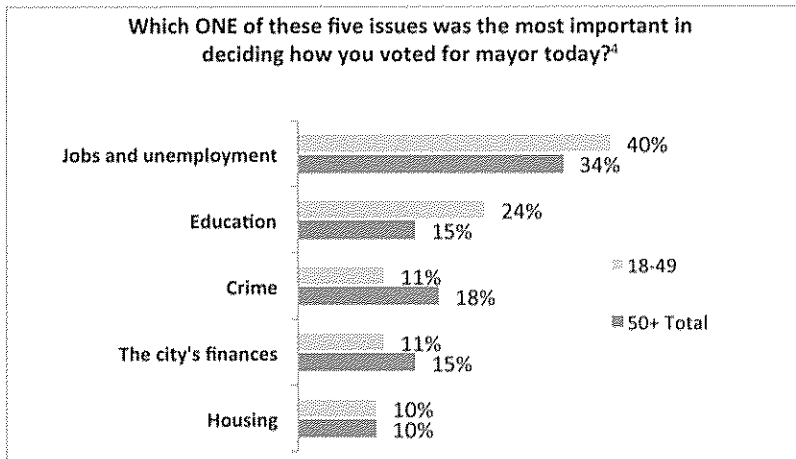
# JOBS AND UNEMPLOYMENT WERE AN IMPORTANT ISSUE ON VOTING DAY FOR ALL AGES

## SHARED VALUES MORE LIKELY TO SWAY 50+ VOTERS; 18-49 WANT CHANGE

Jobs and unemployment ranked first among voters at the polls on election day in 2013 when asked to identify the one issue that was most important in deciding their vote for mayor.<sup>4</sup> Of the issues asked about, 50+ and 18-49 aged voters alike selected jobs and unemployment most often as most important. Education was the second most common issue of importance for 18-49 year olds, while crime was more likely to be important to the 50+.

With regard to candidate qualities, there were more differences between what mattered most to younger and older voters. Younger voters, aged 18-49, were most likely to say they wanted someone who can bring needed change (38%) followed by someone who shares their values (29%). Responses from older voters, aged 50+, to this question were the inverse of their younger counterparts – 35% said shared values mattered most and 28% said being able to bring needed change was most important.

Experience and a belief that that the candidate cares about “people like me” were less likely to be critical to the voting decision among voters in either age group.



AT THE POLLS, ONE THIRD OF 50+ VOTERS SAID JOBS/  
UNEMPLOYMENT WAS THE MOST IMPORTANT ISSUE  
DECIDING THEIR VOTE FOR MAYOR

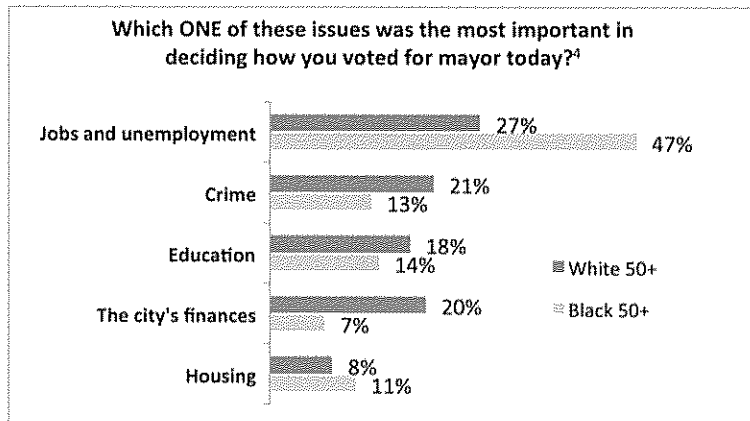
34%



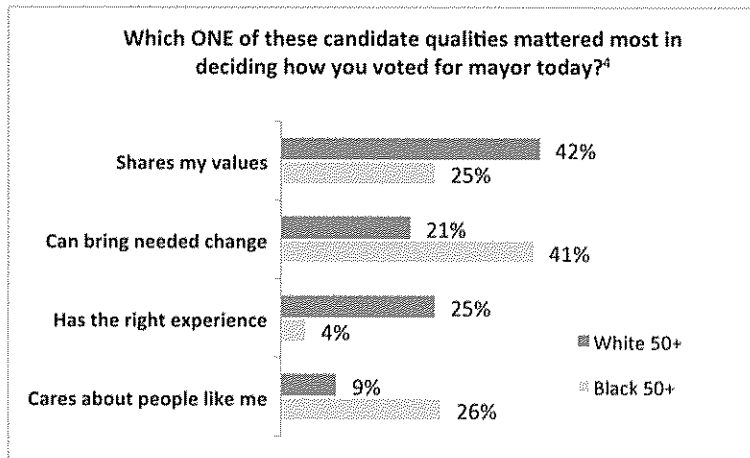
## DECIDING FACTORS ARE STRONGLY CONTRASTED BETWEEN WHITE AND BLACK 50+ VOTERS

**THE 50+ BLACK CONSTITUENCY WANT JOBS AND CHANGE; WHITE 50+ ARE MORE LIKELY TO ENDORSE SOMEONE WITH SHARED VALUES**

Edison Research's exit poll samples did not include enough Hispanic or Asian voters to parse results by age and ethnicity, but we were able to analyze results between White 50+ and Black 50+ voters for insight into voting behaviors between these two constituencies. In both racial groups, more voters said jobs and unemployment was the most important issue deciding their vote for mayor, but for Black voters this issue held a stronger lead. Nearly half of 50+ Black voters (47%) on election day named jobs and unemployment as their number one issue among those listed, compared to just 27% of White 50+ voters.

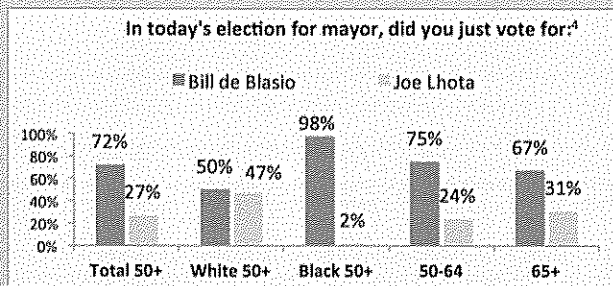


White 50+ voters were comparatively more likely to name crime, education and the City's finances as top issues. The salience of the jobs and employment issue among Black 50+ voters reflects the disparity of unemployment rates between these voter groups in NYC. The self-reported unemployment rate among Black 50-64 year old voters in NYC is 50% higher than White 50-64 year old voters (15% vs. 10%)<sup>7</sup> and as a deciding voting issue it is significantly more important for the 50+ Black constituency overall.



Opinions about the most important candidate qualities were also very divergent between White and Black 50+ voters. Black voter decisions favored a candidate's capacity for bringing change and caring about people like them, while White voters considered shared values and experience to be more important.

**BLACK 50+ VOTERS UNIVERSALLY CAST THEIR BALLOT FOR DE BLASIO. WHITE 50+ VOTES WERE MORE EVENLY BALANCED BETWEEN BOTH CANDIDATES**

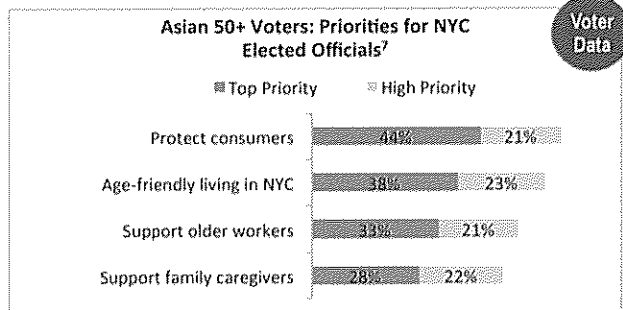
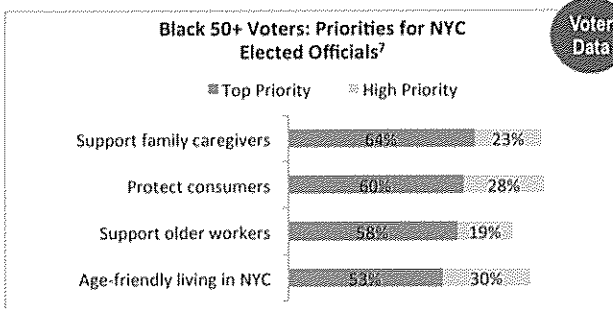
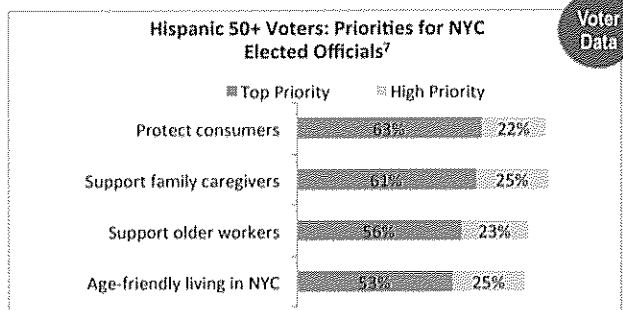
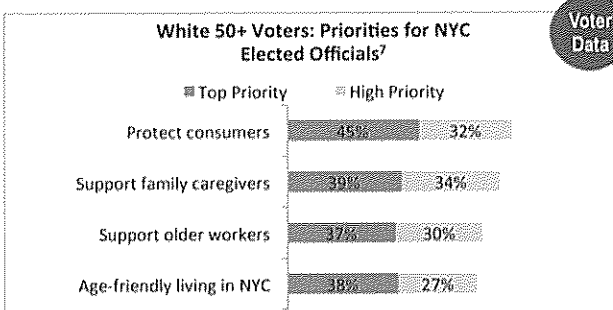
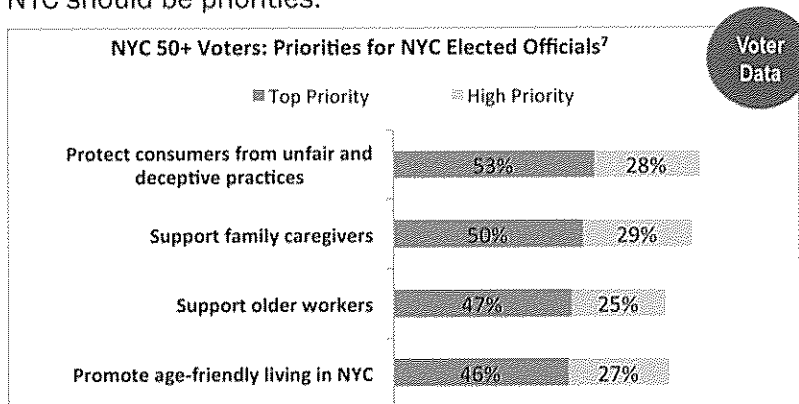


# 50+ VOTERS WANT ELECTED OFFICIALS TO FIGHT FRAUD, SUPPORT CAREGIVERS AND OLDER WORKERS

## FAMILY CAREGIVER SUPPORT RANKS HIGHER WITH BLACK VOTERS; AGE FRIENDLY LIVING RANKS HIGH FOR ASIAN VOTERS

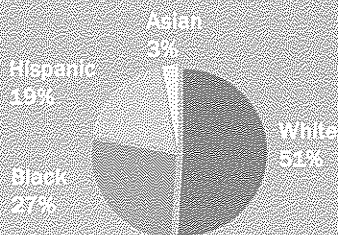
In an AARP survey of 50+ voters, respondents felt very strongly that elected officials in NYC should make fighting fraud and other consumer protections a priority. Eight in ten voters overall want this to be a top (53%) or high (28%) priority for the City's elected officials. A similar proportion want to see support for family caregivers. Nearly three-fourths say legislation in support of older workers and promoting age-friendly living in NYC should be priorities.

Opinions are similar across race and ethnic groups, with some variation in the relative rank order of priorities. Support of family caregivers edges ahead of all other priorities among Black 50+ voters. For Asian voters, age-friendly NYC is a relatively higher priority, ranking just behind fraud and consumer protection.



State of the 50+ in NYC 2014

### 50+ NYC VOTER POPULATION



The following sections of this report will look more closely at some of the key issues of importance for New York City 50+ voters and examine how these issues impact both residents and the City today and in the near future.

#### Section 1: NYC 50+ Voter References

1. *Who Votes? Voter Turnout in New York City*, NYC Campaign Finance Board Voter Assistance Advisory Committee, June 11, 2012. [http://www.nycffb.info/PDF/issue\\_reports/WhoVotes.pdf](http://www.nycffb.info/PDF/issue_reports/WhoVotes.pdf)
2. NYC Election Atlas, 2013, City University of New York, Center for Urban Research. <http://www.nycelectionatlas.com>
3. NYC Board of Elections, Statement and Return Report, November 5, 2013. <http://vote.nyc.ny.us/html/results/results.shtml>
4. 2013 NYC Mayoral Exit Poll Results, Edison Research. 50+ voter results provided to AARP. Total voter results available at <http://www.nytimes.com/projects/elections/2013/general/nyc-mayor/exit-polls.html>.
5. U.S. Census Bureau, 2012 American Community Survey. <http://factfinder2.census.gov>
6. AARP Member Opinion Survey, 2012, NYC sample. Full state and national results and methodology information available here <http://www.aarp.org/about-aarp/info-10-2012/member-opinion-survey-state-reports.html>.
7. AARP Public Opinion Survey of NYC Registered Voters age 50 and older. June 2013. <http://www.aarp.org/nyc50plus>

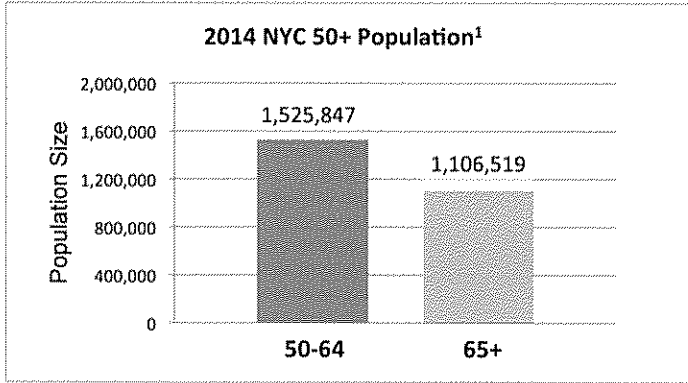
## II. POPULATION & DEMOGRAPHY

- Population size
- Projected growth
- Race/ethnicity, age, borough
- Marital status
- Household composition

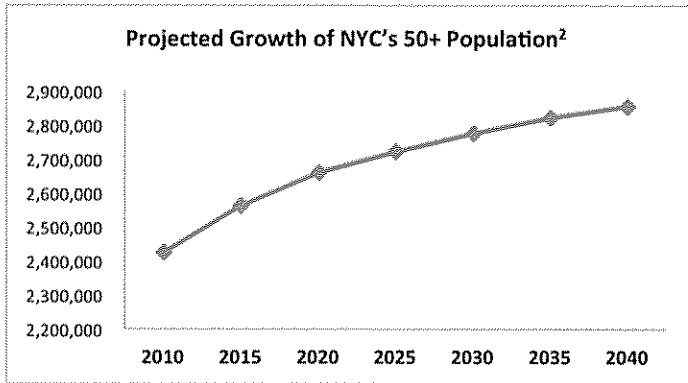
# WITH BOOMERS AGING, NYC IS IN THE MIDST OF RAPID SENIOR POPULATION GROWTH

## AT THE SAME TIME, 50-64 YEAR OLD POPULATION WILL REMAIN STABLE

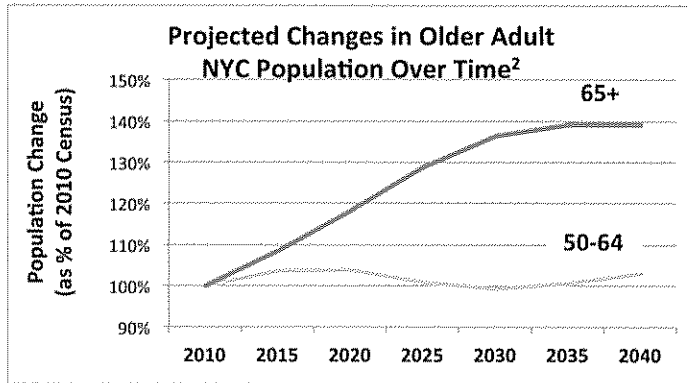
State of the 50+ in NYC 2014



Of New York City's 8.4 million residents living in its five boroughs, 31% or 2.6 million are age 50 and older.<sup>1</sup>



Of the 50+ cohort of older adults, 42% are currently age 65 and older and 58% are between 50 and 64. The larger group of younger baby boomers will drive dramatic growth of the City's older population as they continue to age over the next 15 to 20 years.



Between now and 2040, the City's 50-64 year old population will remain rather flat while the size of the Senior (65+) population will increase close to 40% over the same period. In total, the combined 50+ population will grow 18% over the thirty year period from 2010 to 2040.<sup>2</sup>

**TODAY, NYC'S 1.1 MILLION SENIORS (65+) REPRESENT ABOUT 13% OF THE CITY'S TOTAL POPULATION**

**BY 2030, THE SENIOR POPULATION WILL GROW TO 1.35 MILLION, REPRESENTING 16% OF THE CITY'S TOTAL POPULATION\***

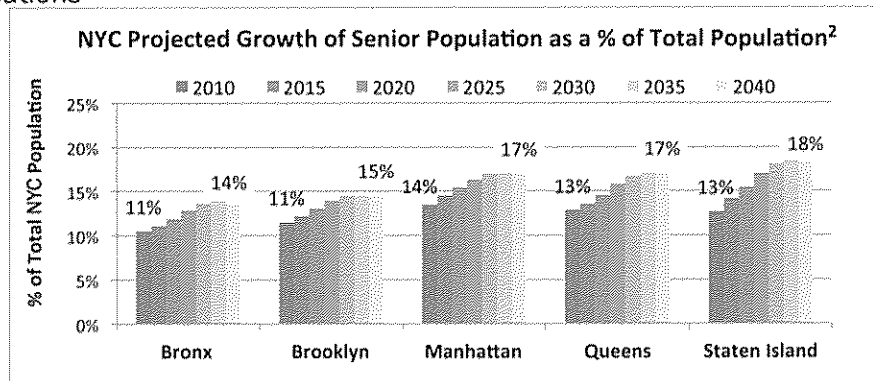
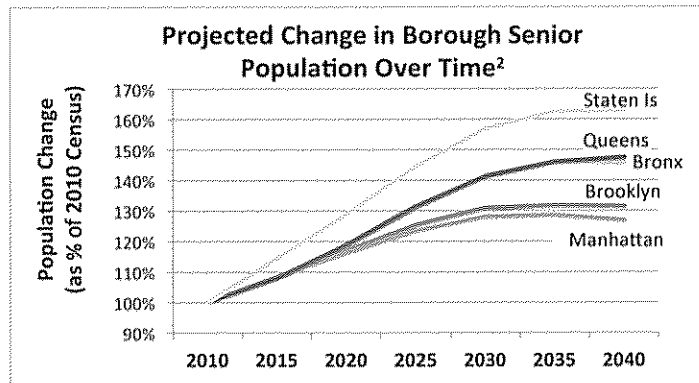
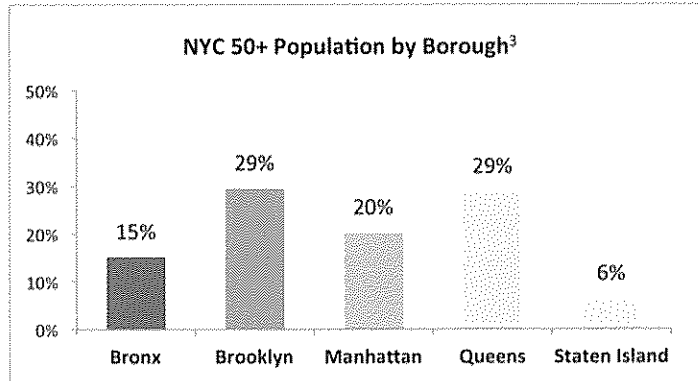
# BOROUGH LEVEL CHANGE IN THE 65+ RANGES FROM 27% TO 63% OVER THE NEXT TWO DECADES

## MORE PROLONGED GROWTH OF OLDER RESIDENTS EXPECTED IN OUTER BOROUGHES

The distribution of the 50+ population across the boroughs roughly approximates that of the total NYC population. Brooklyn and Queens are home to 29% each of the 50+, 20% reside in Manhattan and smaller proportions in the Bronx (15%) and Staten Island (6%).

Within the 50+ demographic, Staten Island's population skews slightly toward the younger end compared to other boroughs, with 62% of the 50+ aged 50-64 and 38% aged 65+. Manhattan's 50+ is the oldest of the boroughs, splitting 56% aged 50-64 and 44% aged 65+.

Partly because its population is already older, Manhattan's 65+ population will grow at a slower rate, though still nearly a 30% increase. The Bronx and Queens will see a 45% increase in their senior populations over the 20+ years. Of the boroughs, Staten Island will experience the steepest senior population growth (63%). As a percentage of the total borough population, Seniors (65+) in Staten Island will rise from 13% to 18% by 2040.

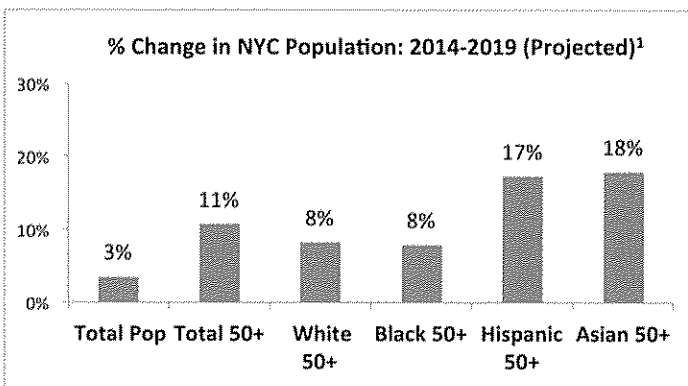
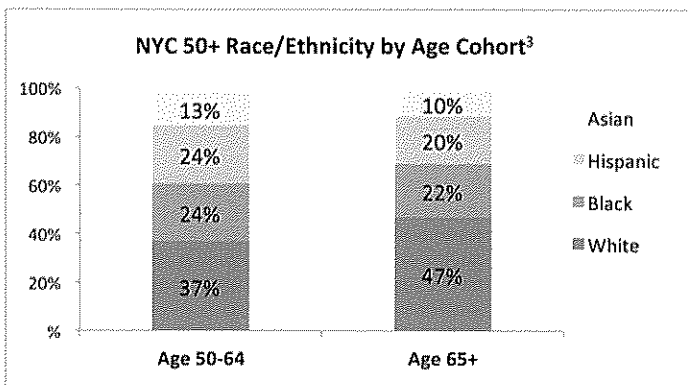
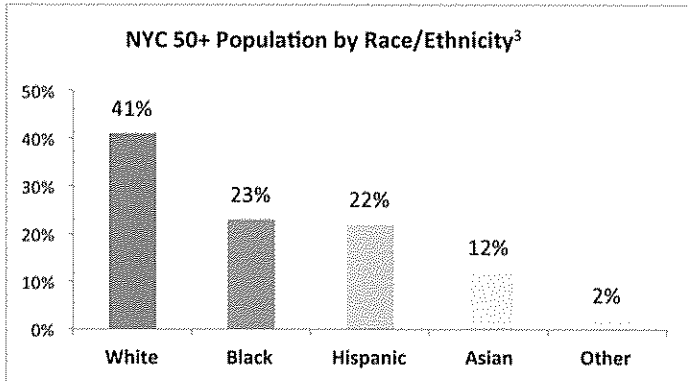


State of the 50+ in NYC 2014

AS A PERCENTAGE OF THE TOTAL POPULATION, GROWTH OF THE 65+ WILL BEGIN TO LEVEL OFF AFTER 2030

# NYC'S 50-64 IS SIGNIFICANTLY MORE DIVERSE THAN THE CURRENT 65+ POPULATION

## MULTICULTURAL NEEDS WILL BE AN INCREASING FACTOR IN COMMUNITY SERVICES FOR SENIORS



Similar to the rest of the NYC population, there is no leading majority race/ethnicity among the 50+. Collectively, non-White groups represent 59% of the 50+ and Whites 41%. Black and Hispanic residents comprise nearly one-fourth each and Asians represent 12% of the City's 50+ population.

In addition to a swelling 65+ population driven by the baby boomer generation, NYC's population is also becoming more diverse similar to the nation overall. Even among 50+ residents, there is a marked distinction in the racial and ethnic representation between 50-64 year olds and those 65+. Whites represent nearly half (47%) of residents 65+ and only 37% of those age 50-64. This shifting demographic means multicultural needs will be an increasing factor in community services for Seniors (65+).

An ongoing rise in diversity is a trend that is expected to continue into the future for the total population as well as the 50+. In the next 5 years, 50+ Asian and Hispanic populations in NYC are expected to grow faster than White and Black cohorts in the same age demographic.

State of the 50+ in NYC 2014

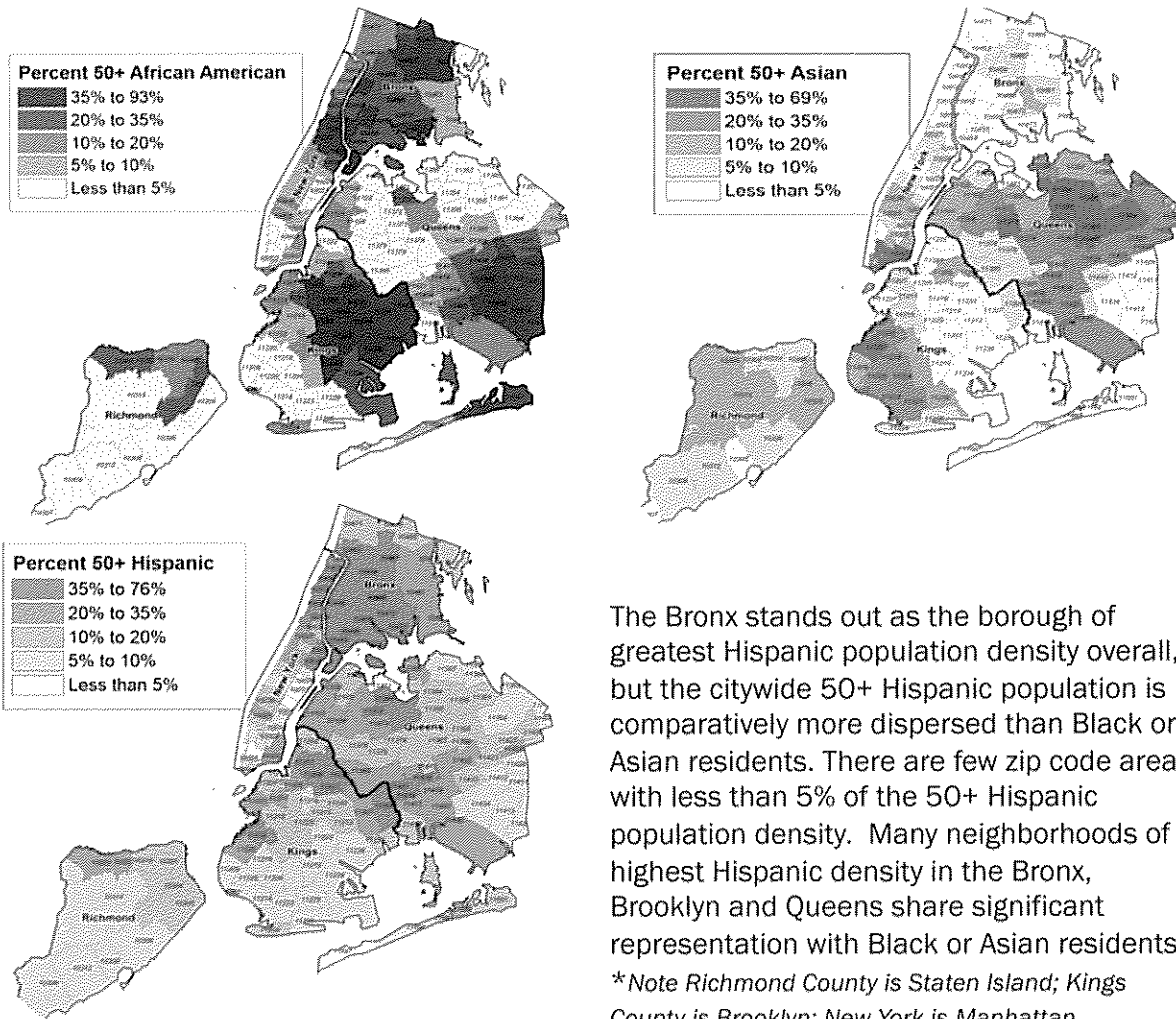
**THE NUMBER OF ASIAN SENIORS IN NYC GREW BY 64% BETWEEN 2000 AND 2010 WITH MOST OF THE NUMERIC GROWTH COMING FROM CHINESE, INDIAN, KOREAN AND FILIPINO SENIORS<sup>5</sup>**

# 50+ BLACK AND ASIAN POPULATIONS ARE CONCENTRATED IN DIFFERENT COMMUNITIES

## HISPANICS LIVE ACROSS ALL BOROUGHES

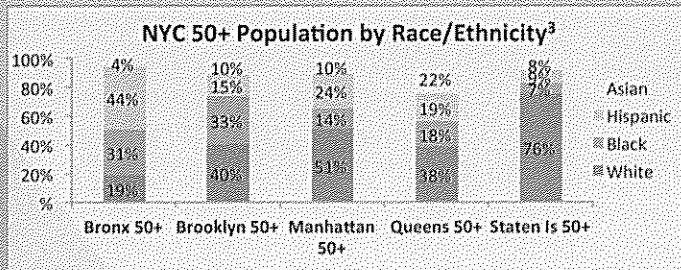
Thematic maps of population density across the boroughs reveal opposite footprints of 50+ African American/Black and Asian communities, with few overlapping areas of highest density between these two groups.<sup>1</sup>

### 2013 NYC 50+ Multicultural Population Density Maps<sup>1</sup>



State of the 50+ in NYC 2014

**THREE OUT OF FIVE BOROUGHS HAVE NO SINGLE MAJORITY 50+ RACE/ETHNICITY**

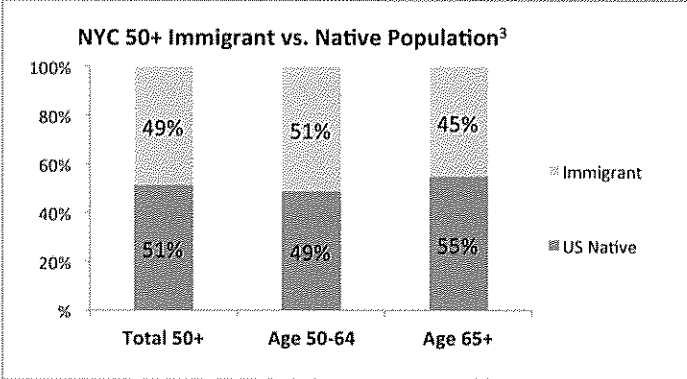


**QUEENS  
22%  
ASIAN**

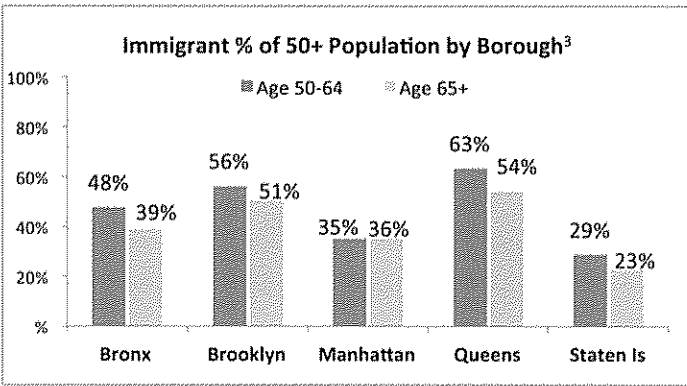


# HALF OF ALL NYC 50+ ARE FOREIGN BORN AND SPEAK A LANGUAGE OTHER THAN ENGLISH AT HOME AMONG SENIORS (65+), ONE IN FIVE ARE ENGLISH ISOLATED

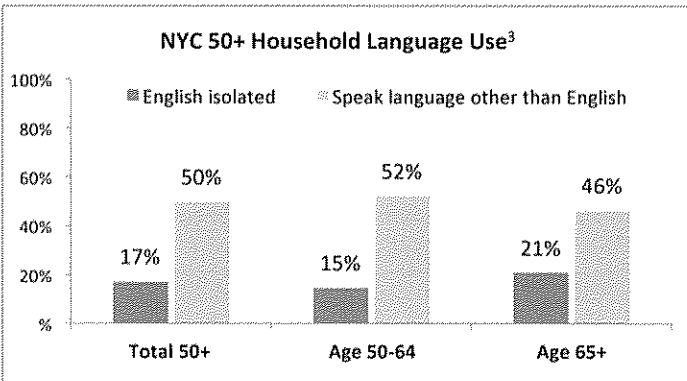
State of the 50+ in NYC 2014



Thirty-seven percent of the City's total population is foreign born. Among the 50+ cohort, it is an even larger proportion – nearly half (49%) of all NYC residents age 50 and older are foreign born. As a group, current 50-64 year olds are even more likely to be foreign born than those 65+ (51% versus 45%). Across the boroughs, Queens has the largest representation of immigrants (60%) among its 50+ population followed by Brooklyn (54%).



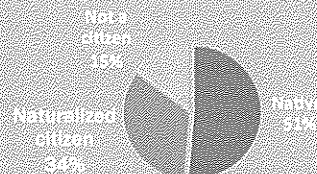
Even though the 50-64 year old group is more likely to be foreign born, they are less likely to be English isolated households, tending more toward bilingual household language use. As measured by the Census Bureau, “English isolated households” are those where no member above age 14 speaks English very well.<sup>3</sup> This extreme form of language barrier is lower among 50-64 year olds than 65+, but still a majority (52%) are speaking a language other than English in their homes. Spanish accounts for less than half of them (24% of all 50-64 households).



Among the boroughs, English isolation is highest in Brooklyn where 26% of senior (65+) households are language isolated.

**THE MAJORITY OF NYC IMMIGRANTS AGE 50 AND OLDER ARE NATURALIZED CITIZENS**

NYC 50+ Population by Citizenship<sup>3</sup>



# MAJORITY OF OLDER NYC RESIDENTS ARE FEMALE AND SINGLE

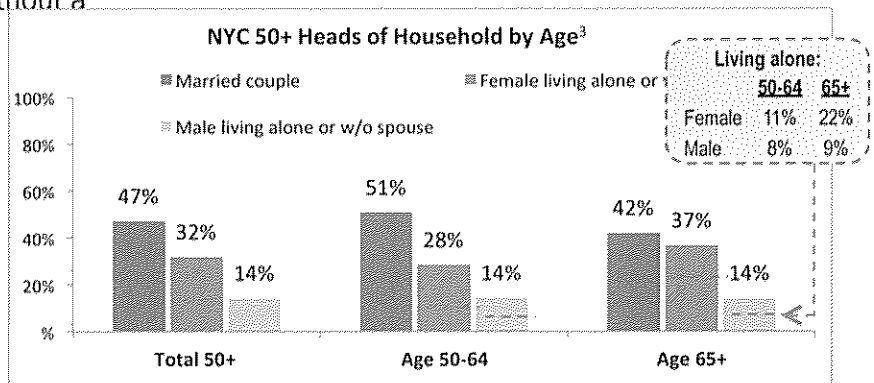
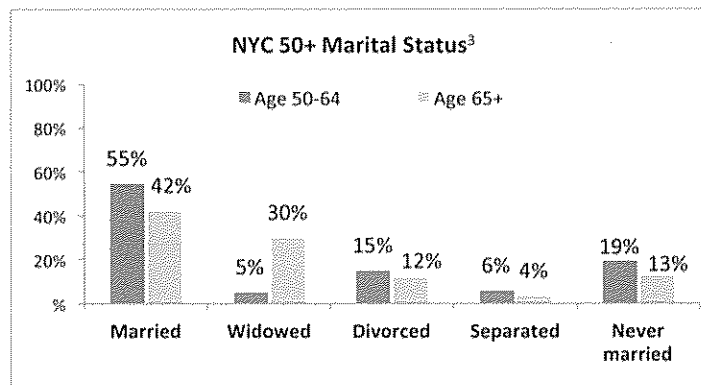
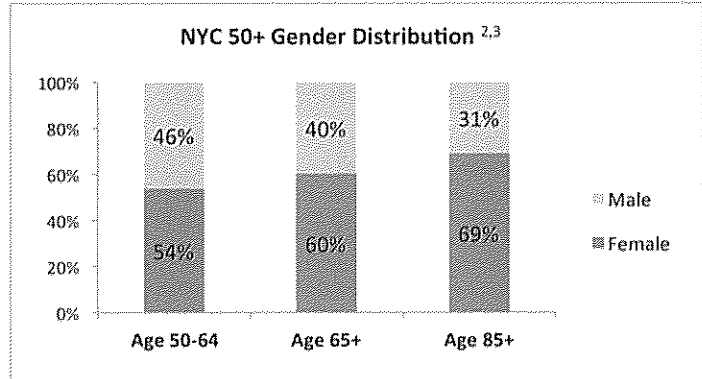
## WHETHER BY CHOICE OR CIRCUMSTANCE, WOMEN ARE GOING IT ALONE

Women live longer than men so it follows that NYC's population skews more heavily female in older age cohorts. Even among residents age 50-64, there are slightly more women (54%) than men (46%), rising to 60% female among Seniors (65+) and up to 69% female by ages 85 and older.

In addition to an uneven gender ratio, many older City residents are likely to be single. Among NYC 50-64 year olds, about one-fifth (19%) have never married and another one-fourth (26%) are otherwise single. At ages 65 and above, nearly one-third (30%) are widowed and 16% were previously married but not currently.

As a result, NYC 50+ households are more likely to be headed by women than men. In fact, households headed by women (80%) living alone or with a spouse are as common as those headed by single men (14%).

Moreover, the proportion of households headed by women living alone rises significantly with age, doubling from 11% in the 50-64 age group to 22% among the 65+, while the proportion of men living alone remains constant.

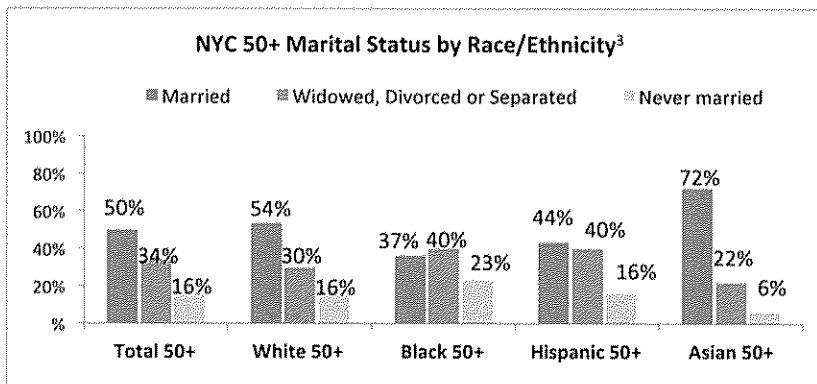


IN 1960, 70% OF ALL U.S. ADULTS WERE MARRIED. TODAY, IT'S 51%

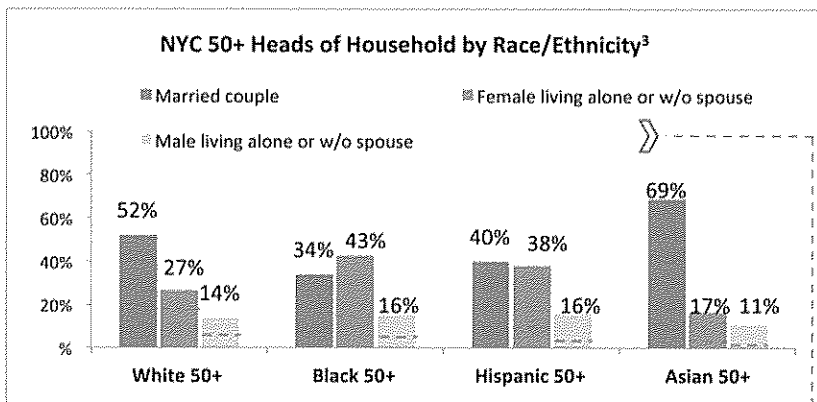
AT AGES 55 AND ABOVE, WOMEN LIVING ALONE IN THE U.S. OUTNUMBER MEN LIVING ALONE<sup>9</sup>

## SINGLE FEMALES ARE EVEN MORE LIKELY TO BE AT THE HEAD OF 50+ BLACK AND HISPANIC HOUSEHOLDS FOUR IN TEN HEADS OF HOUSEHOLD ARE WOMEN WITHOUT A SPOUSE

Although half of all 50+ NYC residents are married, marriage rates vary across racial and ethnic groups. Married civil status is less likely among 50+ Black (37%) and Hispanic (44%) residents and two in five (40%) in both groups have been formerly married (widowed, divorced or



separated). In contrast, Asians present significantly higher marriage rates (72%) and the proportion who have never married is very small (6%).



There are similar patterns in the types of 50+ heads of household by race and ethnicity. Both Blacks and Hispanics have higher levels of single female households – about four in ten. Hispanic households are equally as likely to be headed by women alone as by married couples, whereas in 50+ Black households, single women heads of household are most common.

Living alone:	White			African American			Hispanic			Asian		
	50+	50-64	65+	50+	50-64	65+	50+	50-64	65+	50+	50-64	65+
Female	19%	12%	26%	16%	12%	23%	13%	9%	20%	7%	4%	11%
Male	10%	10%	10%	9%	8%	9%	7%	6%	8%	3%	3%	3%

An increase in the proportion of women living alone at ages 65 and older is consistent across all race and ethnic groups. Of note, a majority of White unmarried female heads of household live alone and are less likely than their Black, Hispanic or Asian female counterparts to have other people in their home.

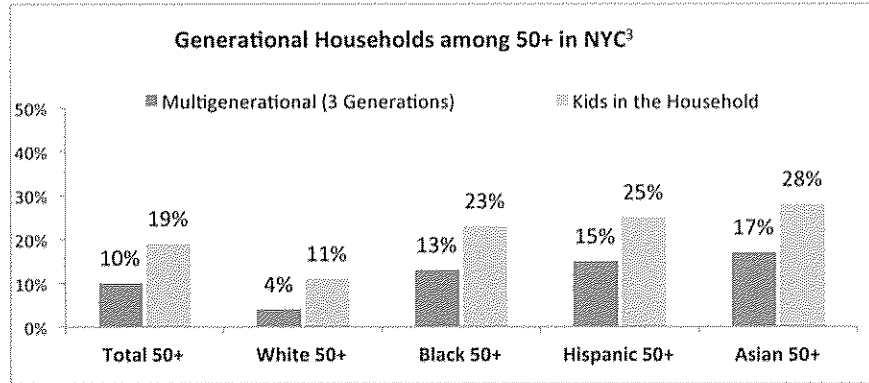
### WOMEN, BLACKS AND HISPANICS ARE OVER-REPRESENTED AMONG SENIOR NEW YORK CITY HOUSING AUTHORITY RESIDENTS (AGE 65+)

	NYC Housing Authority Residents Aged 65+ <sup>7</sup>	Total NYC Population Aged 65+ <sup>3</sup>
Male	29%	40%
Female	71%	60%
White	9%	47%
Black	40%	22%
Hispanic	44%	20%
Asian and other	7%	11%
Living alone	53%	31%

# INTERGENERATIONAL LIVING IS MORE COMMON AMONG MULTICULTURAL RESIDENTS

## NOT-SO-EMPTY NESTS ARE REALITY FOR MANY

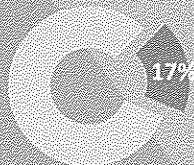
One in five New York City residents age 50 and older have children in their household; one in ten have three generations living together. In non-White families, multigenerational living and the presence of children in the household is significantly more common.



For Black, Hispanic and Asian residents between 50 and 64 years old, more than one-fourth live in households with children present. By age 65, the presence of children diminishes substantially for Whites and less so for non-White groups. Asian residents in particular maintain a higher incidence of living with children as Seniors and are most likely to live in multigenerational households in older age. A full fourth of Asian Seniors (age 65+) live in a multigenerational household, more than twice the level of Seniors at large (11%).<sup>3</sup>

	Total NYC		White		Black		Hispanic		Asian	
	Age 50-64	Age 65+	Age 50-64	Age 65+	Age 50-64	Age 65+	Age 50-64	Age 65+	Age 50-64	Age 65+
3 generation household	10%	11%	4%	4%	13%	14%	15%	16%	13%	24%
Kids in the household	24%	11%	17%	3%	28%	16%	29%	17%	30%	23%

### Grandparents & Kin Care



**17% OF 50+ GRANDPARENTS REGULARLY PROVIDE CARE OR FINANCIAL SUPPORT FOR THEIR GRANDCHILDREN OR KIN'S CHILDREN<sup>8</sup>**

## Section 2: Population & Demography References

1. Nielsen, 2014. Prepared by AARP Research.
2. Cornell Program for Applied Demographics, projections based on 2010 Decennial Census data. Prepared by AARP Research. Data available at <http://pad.human.cornell.edu/counties/projections.cfm>. Accessed on October 23, 2013.
3. U.S. Census Bureau, American Community Survey, PUMS 2009-2011. Prepared by AARP Research.
4. NYC Dept. of City Planning, 2010 Population Data available at [http://www.nyc.gov/html/dcp/html/census/demo\\_tables\\_2010.shtml](http://www.nyc.gov/html/dcp/html/census/demo_tables_2010.shtml). Accessed on October 23, 2013
5. Asian American Federation, 2012. *Asian Americans in New York City: A Decade of Dynamic Change 2000-2010*. Available at [http://www.aafny.org/pdf/AAF\\_nyc2010report.pdf](http://www.aafny.org/pdf/AAF_nyc2010report.pdf)
6. Klinenberg, Eric. *Going Solo: The Extraordinary Rise and Surprising Appeal of Living Alone*. The Penguin Press, 2012. Excerpt available at [http://finance.fortune.com/2012/01/25/eric-klinenberg-going-solo/?iid=SF\\_F\\_Lead](http://finance.fortune.com/2012/01/25/eric-klinenberg-going-solo/?iid=SF_F_Lead).
7. *Health of Older Adults in New York City Public Housing: Findings from the New York City Housing Authority Senior Survey*. May 2011. Available at <http://www.nyc.gov/html/nycha/downloads/pdf/senior-report-nycha.pdf>
8. AARP NY Legislative Issue Survey of 50+ Registered Voters, NYC sample. December 2012.

2.6MM 2014 NYC 50+

# III. JOBS & WORK

- Employment
- Age Discrimination in the Workplace
- Working Caregivers

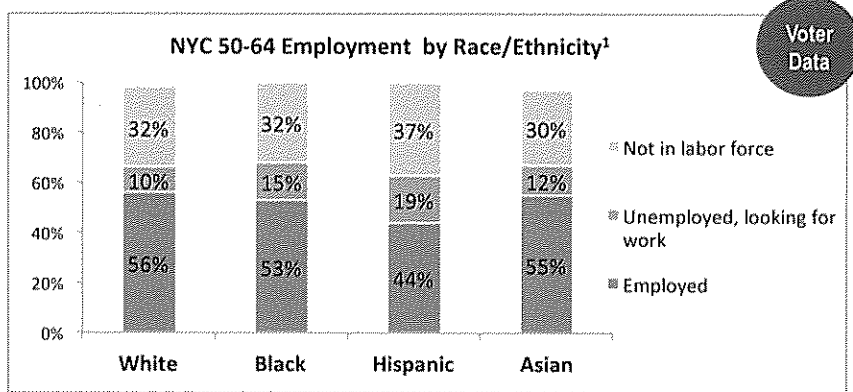
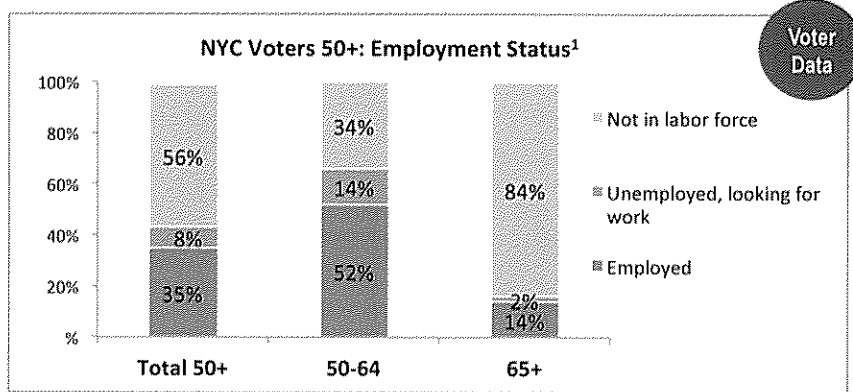
# TWO-THIRDS OF 50-64 YEAR OLD NYC VOTERS ARE IN THE LABOR FORCE

## YET HIGH UNEMPLOYMENT IS REPORTED AMONG BOOMER VOTERS

For many Americans, ages 50-64 are their prime working years and often when they are highest paid. While half of all 50-64 year old voters in NYC are currently working, as of June 2013 one in seven or 14% polled voters were unemployed and looking for work. This is significantly higher than the citywide unemployment rate of 8.7% for the same time period reported by the NY State Department of Labor.<sup>1,2</sup>

Employment status of NYC voters age 50-64 also vary by race/ethnicity groups according to AARP's poll. Hispanic voters age 50-64 were least likely to be currently employed with one in five (19%) unemployed and looking for work – the highest of any race or ethnic group.<sup>1</sup>

Although more adults in America are delaying retirement and working into older age more than ever before, the majority of NYC voters age 65 and older are no longer in the labor force (84%).<sup>1,3</sup>



14%

SELF-REPORTED UNEMPLOYMENT AMONG 50-64 YEAR OLD NYC VOTERS (JUNE 2013)<sup>1</sup>

## EDUCATIONAL, HEALTH, AND SOCIAL SERVICES ARE THE TOP NYC INDUSTRIES OF EMPLOYMENT FOR AGES 50-64 FOLLOWED BY ARTS, ENTERTAINMENT AND HOSPITALITY

The economically powerful NYC provides a variety of employment opportunities. According to the US Census Bureau which collects data on businesses as well as individuals, education, health, and social services are the top industries of employment for NYC adults age 50-64 across all racial and ethnic groups, and most significantly for Black residents where these sectors represent 44% of jobs. Hospitality (accommodation, food services) together with arts and entertainment rank a close second for Asians. At the same time, Whites have higher rates of employment in professional and scientific services than other race/ethnic groups in NYC.<sup>4</sup>

NYC 50+ Industry of Employment <sup>4</sup>	White 50-64	Black 50-64	Hispanic 50-64	Asian 50-64
Educational, health and social services	31%	44%	31%	25%
Professional and scientific services	15%	8%	9%	7%
Finance, insurance, real estate	12%	7%	9%	7%
Arts, entertainment, accommodation, food services	11%	10%	16%	23%
Retail	6%	5%	8%	11%
Public administration	5%	7%	4%	3%
Transportation	5%	10%	8%	9%
Construction	4%	4%	5%	4%
Manufacturing	4%	3%	7%	8%
Information	4%	2%	1%	1%

State of the 50+ in NYC 2014

Although service industries appear to represent the lion's share of work opportunities for New Yorkers 50+, there has also been a marked decline in NYC employer-sponsored retirement plans particularly in service industries. A 2012 report by the NYC Comptroller's office analyzed the availability of employer-sponsored retirement plans and revealed that industries such as personal services; entertainment and recreational services; and wholesale and retail trade industries were among those with the lowest plan sponsorship as of 2009. Further, occupations in these industries have experienced the steepest declines in plan sponsorship since 2000. The analysis concluded that employer decisions across all industries and occupations were the primary driver in declining plan sponsorships rather than changing demographics of workers. According to that report, workers in all service industries generally experienced a decline in plan sponsorship and by a larger margin in NYC compared to the nation as a whole.<sup>5</sup>

NYC Retirement Plan Sponsorship Rates by Select Industries<sup>5</sup>

	2000	2009	% change
Total Sponsored	48%	40%	-18%
Entertainment & Recreational Services	43%	19%	-57%
Wholesale & Retail Trade	34%	19%	-44%
Personal Services	26%	15%	-42%
Business & Repair Services	48%	34%	-29%
Manufacturing	42%	45%	+8%

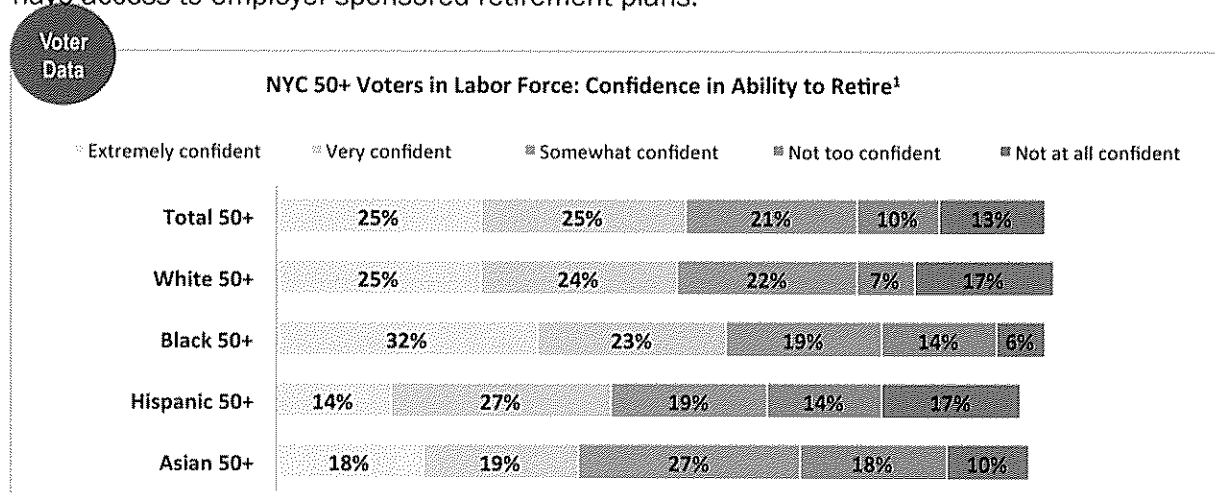
**FEWER THAN ONE IN FIVE  
NYC WORKERS IN  
ENTERTAINMENT AND  
RECREATIONAL SERVICES  
HAVE ACCESS TO  
SPONSORED PLANS**



# LAGGING RETIREMENT READINESS UNDERSCORES THE NEED TO ENSURE LONGEVITY FOR NYC'S OLDER WORKERS

## RETIREMENT READINESS IS WEAKEST FOR HISPANIC AND ASIAN WORKERS

NYC 50+ workers are not immune to the economic forces delaying or indefinitely postponing Americans' retirement plans across the country. Such reasons include losses in financial portfolios, declines in housing values, lack of retirement savings or employer-sponsored plans, and the need to work for health care coverage. Among NYC working 50+ voters, just half are confident they will be able to retire at some point, and nearly one in four are not confident in their ability to retire at any point and face the prospect of working for the rest of their lives. Retirement confidence is weakest among Hispanics and Asians, two NYC worker groups that are less likely to have access to employer-sponsored retirement plans.<sup>1,5</sup>



Due to this downward trend in retirement plan sponsorship, older workers will need to be more reliant on their own personal investments or with fewer resources in older age, will need to work longer. This is another dynamic that will push New York City toward an older workforce in the coming years.

NYC Retirement Plan Sponsorship Rates by Worker Race/Ethnicity <sup>2</sup>	2000	2009	% change
Total Sponsored	48%	40%	-17%
White	59%	53%	-10%
Black	48%	38%	-21%
Hispanic	35%	30%	-14%
Asian	39%	26%	-33%

**COMPARED TO WHITE WORKERS, BLACK, HISPANIC AND ASIAN WORKERS STARTED AT A RELATIVE DISADVANTAGE IN RETIREMENT PLAN ACCESSIBILITY AND LOST MORE GROUND SINCE 2000<sup>2</sup>**

# MANY 50+ IN NYC HAVE EXPERIENCED OR WITNESSED AGE DISCRIMINATION IN THE WORKPLACE ENCOURAGED OR FORCED RETIREMENT IS MOST COMMON

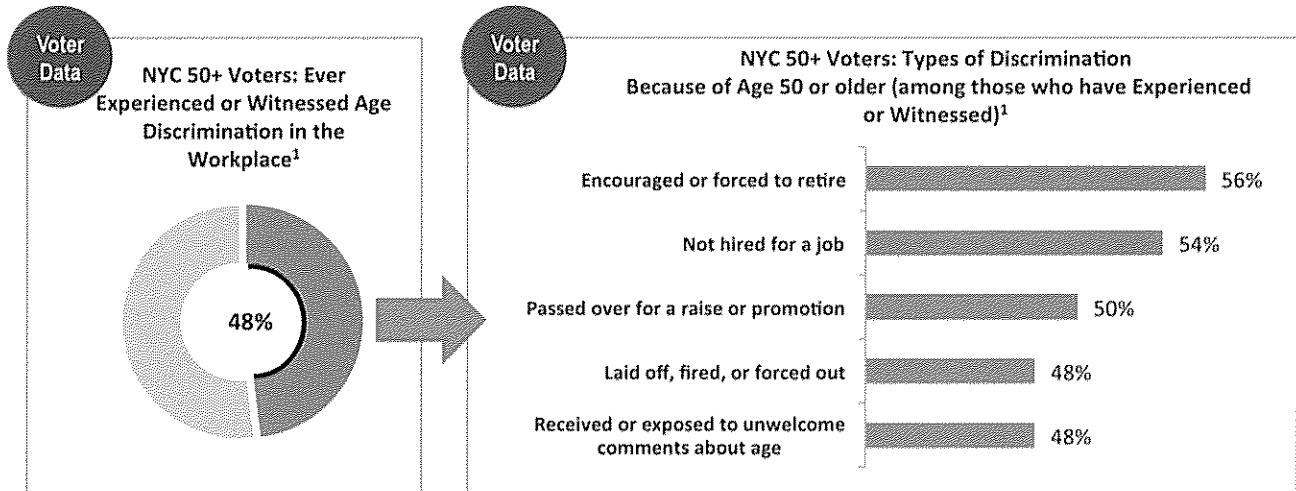
Percent Increase in Employment by Age and Gender, 1977-2007 <sup>7</sup>	
Age 16 and over	59%
Age 65 and over	101%
Men, Age 65 and over	78%
Women, Age 65 and over	147%
Age 65-69	85%
Age 70-74	98%
Age 75 and over	172%

Older workers are delaying retirement and staying in the workforce in record numbers.<sup>6</sup> Over the last 30 years, people age 65 and older in the workplace increased over 100%, driven primarily by more older working women as well as workers in the oldest age cohort of 75+.<sup>7</sup> In 2013, one in three Americans in their late 60s were in the workforce, the most ever on record.<sup>2</sup>

With this demographic shift in our labor force, more generations are sharing the workplace and older workers confront hazards of age discrimination at work.

Age discrimination involves treating someone (an applicant or employee) less favorably because of their age and it tends to be more prevalent in weak labor markets.<sup>8</sup> In NYC, almost half (48%) of 50+ voters have experienced or witnessed at least one type of workplace discrimination related to age.

Being encouraged or forced to retire, as well as not being hired for a job were the top types of age discrimination witnessed or experienced by NYC 50+ voters.<sup>1</sup> Among Boomer voters (50-64) who are currently working, age discrimination rates are even higher with 53% experiencing or witnessing at least one type of age-based discrimination since turning 50.<sup>1</sup>

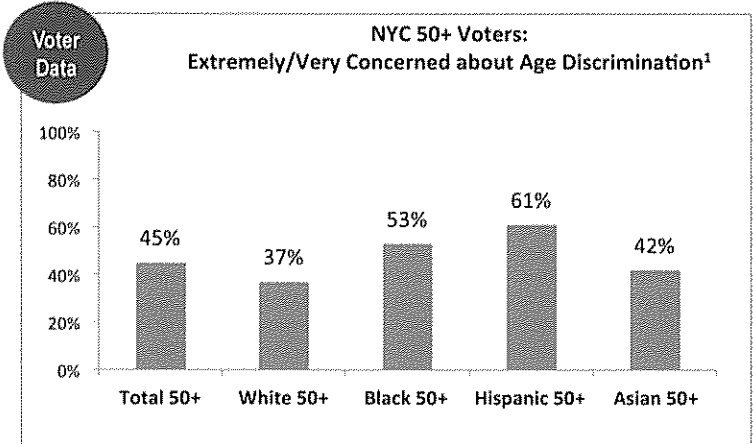
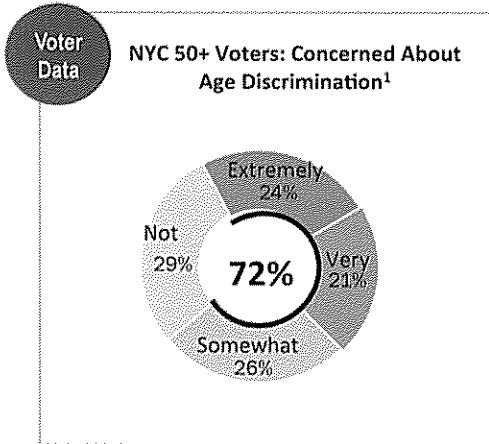


IN 2013, THE NATIONAL LABOR FORCE PARTICIPATION RATE FOR SENIORS (65+) WAS 19.2%, THE HIGHEST RATE SINCE 1964<sup>3</sup>

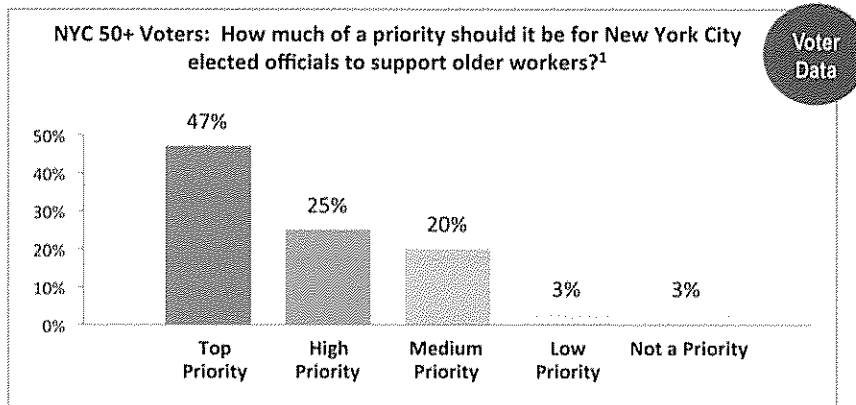
# SEVEN IN TEN ARE CONCERNED ABOUT WORKPLACE AGE DISCRIMINATION

## VOTERS SAY SUPPORTING OLDER WORKERS SHOULD BE A TOP PRIORITY FOR NYC OFFICIALS

While most NYC 50+ voters have experienced or witnessed age discrimination in the workplace, even more are worried about it. Seven in ten 50+ voters in NYC are extremely, very, or somewhat concerned about age discrimination at work. Blacks, Hispanics, and Asians are more likely than Whites to be intensely concerned about age discrimination against older workers.



With lagging retirement readiness, most 50+ need to remain in the workforce to stay self sufficient and maintain their quality of life. The need to continue working combined with observations of, or experience with, perceived age discrimination has resulted in heightened concerns. A majority of 50+ NYC voters say it should be a priority for NYC elected officials to work on laws, regulations and policies that support older workers.



**48%**

**NYC 50+ VOTERS WHO HAVE EXPERIENCED OR WITNESSED 50+ AGE DISCRIMINATION IN THE WORKPLACE<sup>1</sup>**

# MANY 50+ WORKERS ARE ALSO FAMILY CAREGIVERS TO ADULT LOVED ONES

## CAREGIVING DEMANDS INTERRUPT WORK CONTINUITY FOR 50+

In addition to age discrimination, another challenge for many older workers is balancing work with family caregiving responsibilities. The “average” caregiver is a woman in her early 50’s who works outside the home and provides unpaid care to their parent.<sup>9</sup> In order to juggle caregiving responsibilities with work, employed caregivers often experience strain on their work life. Nationally, nearly seven in ten (68%) caregivers report making work accommodations because of caregiving, including arriving late/leaving early or taking time off, cutting back on work hours, changing jobs, or stopping work entirely.<sup>9</sup>

Caregivers who leave or cut back on work give up not only foregone earnings and Social Security benefits, but they also can lose job security, career mobility, and employment benefits such as health insurance and retirement savings potentially making them more likely to rely on public assistance themselves in old age.<sup>9</sup>

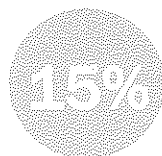
In NYC, nearly half (47%) of 50-64 year old working voters are caregivers or have been a caregiver in the past five years. Among working caregivers, two-thirds (66%) report “a good deal” to “overwhelming” levels of strain on their quality of life from their caregiving responsibilities, including financial hardship, emotional stress and stress at work. Finally, one in six working NYC caregivers have felt treated unfairly by employers or in their workplace because of their caregiving responsibilities.<sup>1</sup>



Of 50-64 year old workers in NYC are family caregivers



Of all working caregivers feel a “good deal” to “overwhelming” strain on their quality of life



Of all working caregivers have felt treated unfairly at work due to caregiving responsibilities

**51% OF NYC'S 50+ FAMILY CAREGIVERS OF ADULT LOVED ONES ARE IN THE LABOR FORCE: 41% CURRENTLY WORKING AND 10% LOOKING FOR WORK<sup>1</sup>**

# FLEXIBLE WORKPLACE POLICIES ALLOW CAREGIVERS TO CONTINUE WORKING

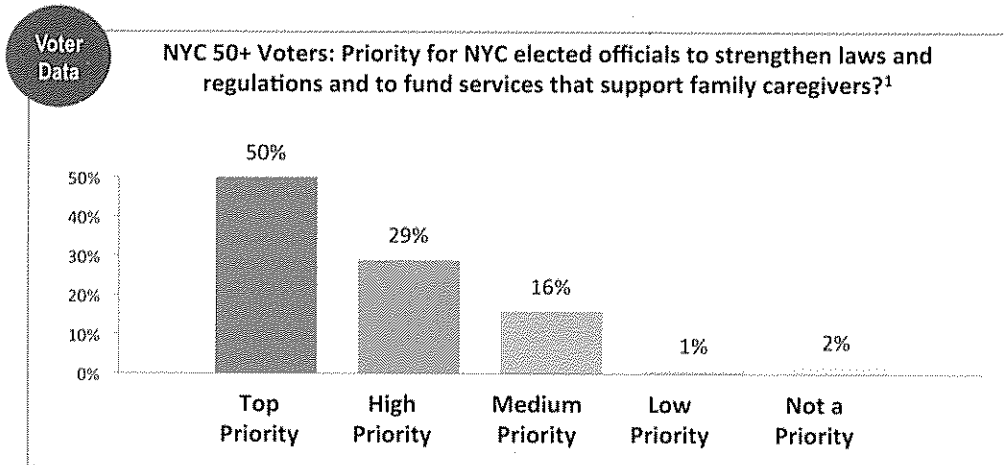
## CAREGIVING PROTECTIONS AND LEAVE POLICIES STABILIZE THE WORKFORCE, BENEFIT EMPLOYEES AND THEIR FAMILIES

In its research on paid sick leave in NYC, the Community Service Society (CSS) found that half of all NYC workers had no sick leave in 2011, and seven out of ten working poor did not have a single paid sick day. In its report "Still Sick in the City", the CSS stated the lack of paid sick time was especially high in occupations that most commonly employ 50-64 workers, and in particular multicultural workers, such as education, health, social services and food services.<sup>10</sup>

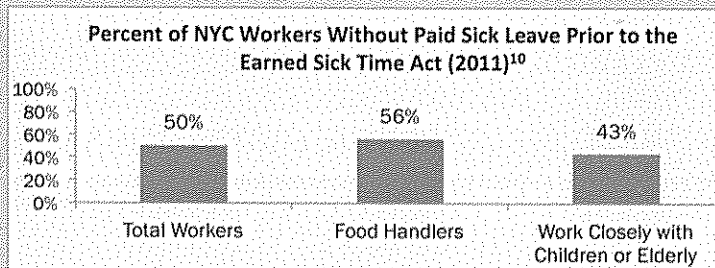
The Earned Sick Time Act passed into law by the New York City Council in June 2013 directly benefited 50-64 year old workers by giving them more time to care for themselves and their loved ones.

Workplace policies must adapt to the needs of workers in order to build a stable workforce. It will be important to continue policy changes like the Earned Sick Time Act that ensure protections for caregiving and promote flexible policies to accommodate the needs of an increasingly older workforce.

Regardless of whether or not they are currently caregivers themselves, nearly all 50+ NYC voters indicate that strengthening laws and regulations to support family caregivers should be a priority for NYC elected officials.



**PRIOR TO NYC'S EARNED SICK TIME ACT, HALF OF ALL NYC WORKERS HAD NO PAID SICK LEAVE<sup>10</sup>**



### Section 3: Jobs & Work References

1. AARP Public Opinion Survey of NYC Registered Voters age 50 and older. June 2013. <http://www.aarp.org/nyc50plus>
2. NY Local Area Unemployment Rates, June 2013. NY State Department of Labor. Press release with link to the report available at <http://www.labor.ny.gov/pressreleases/2013/july-23-2013.shtml>
3. The Job Market has a Senior Moment by Ben Steverman, June, 2013. Available at <http://www.bloomberg.com/news/2013-06-21/the-job-market-has-a-senior-moment.html>
4. U.S. Census Bureau, American Community Survey, PUMS 2009-2011. Prepared by AARP Research.
5. Are New Yorkers Ready for Retirement? Trends in Plan Sponsorship, Participation, and Preparedness. New York City Comptroller's Office, Budget & Policy Bureau. Available at <http://comptroller.nyc.com/rsnyc/reports.asp?f=4>
6. Pew: Older Workers Don't Crowd Out Younger Workers For Jobs. [web log]. September 2013. Available at [http://blog.aarp.org/2012/09/13/pew-older-workers-dont-crowd-out-younger-workers-for-jobs/?intcmp=AF\\_BI\\_II\\_BI](http://blog.aarp.org/2012/09/13/pew-older-workers-dont-crowd-out-younger-workers-for-jobs/?intcmp=AF_BI_II_BI).
7. Bureau of Labor Statistics. Spotlight on Statistics: Older Workers. June 2008. Available at [http://www.bls.gov/spotlight/2008/older\\_workers/data.htm#chart\\_01](http://www.bls.gov/spotlight/2008/older_workers/data.htm#chart_01)
8. U.S. Equal Employment Opportunity Commission. Types of Discrimination. Available at <http://www.eeoc.gov/laws/types/age.cfm>.
9. *Valuing the Invaluable: 2011 Update. The Growing Contributions and Costs of Family Caregiving.* The AARP Public Policy Institute. 2011. Available at <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html>
10. *Still Sick in the City, What the Lack of Paid Leave Means for Working New Yorkers.* Community Service Society, January 2012. Available at <http://www.cssny.org/publications/entry/still-sick-in-the-city-january-2012>

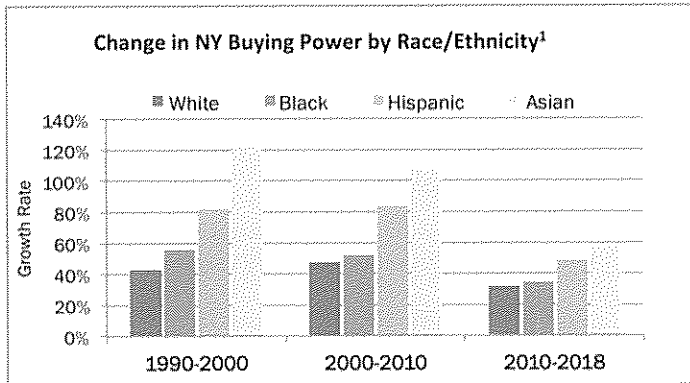
# IV. ECONOMIC SECURITY

- Buying Power
- Fraud & Identity Theft
- Affordable Housing
- Retirement Readiness
- Household Income
- Sources of Income
- Poverty
- Food Insecurity

# 50+ NYC RESIDENT CONSUMER EXPENDITURE SURPASSED \$70 BILLION IN 2011<sup>2</sup>

## MULTICULTURAL BUYING POWER IS GROWING RAPIDLY

Buying power or purchasing power is the amount of money available to purchase products. Buying power is a marketplace driver because knowing the buying power of a consumer group can influence product and service offerings in the marketplace.

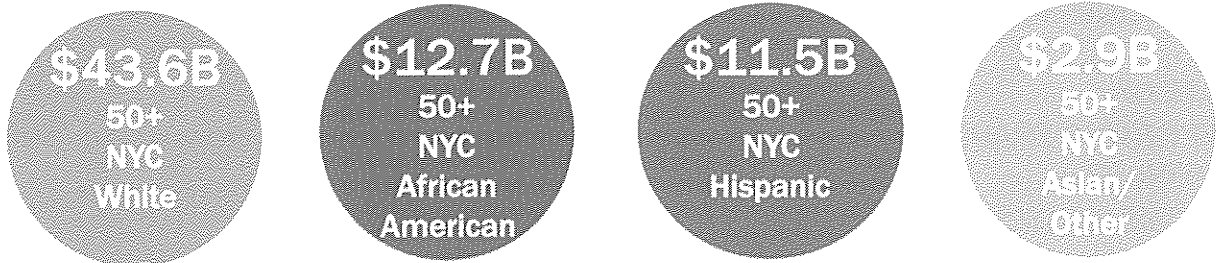


The Selig Center for Economic Growth estimates that New York State's total buying power will rise from \$800 billion in 2010 to \$1.1 trillion for 2018. Percentage-wise, from 2000-2018, NY state total buying power is expected to rise by 34 percent and researchers predict that the buying power and economic clout of non-White populations will continue to increase at a faster rate than that of Whites.<sup>1</sup>

In a separate analysis of 2011 consumer spending from the Bureau of Labor Statistics, AARP'S Public Policy Institute estimated that the total expenditure of consumer units residing in New York City was \$142 billion. About half of that spend or \$70.1 billion was from New Yorkers age 50 and older. Almost 40% of all 50+ consumer expenditure is represented by African American, Hispanic and Asian New Yorkers combined.<sup>2</sup>

State of the 50+ in NYC 2014

### ESTIMATED CONSUMER EXPENDITURE OF 50+ NEW YORKERS<sup>2</sup>



MULTICULTURAL CONSUMERS REPRESENT 40% OF ALL 50+ CONSUMER EXPENDITURE IN NYC<sup>2</sup>



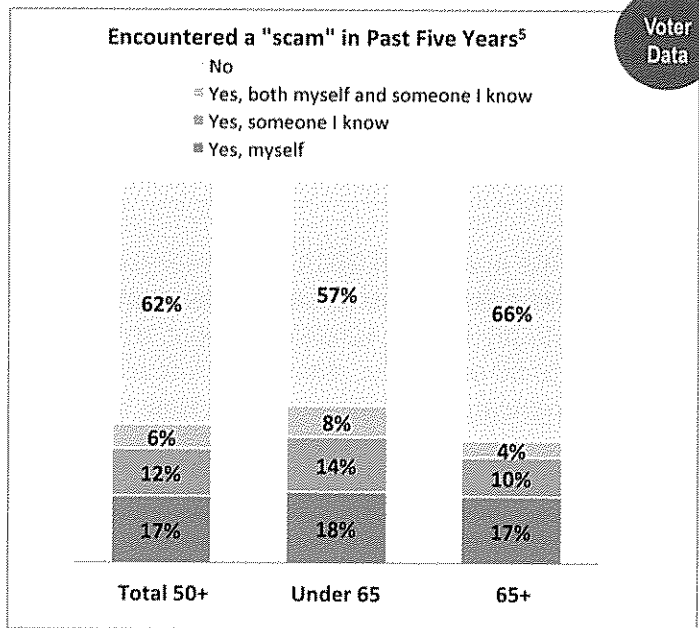
## FRAUD IS COMMONLY EXPERIENCED BY NYC 50+ ONE IN THREE NYC 50+ VOTERS HAVE ENCOUNTERED A SCAM OR FRAUD

Identity theft and fraud are “terms used to refer to all types of crime in which someone wrongfully obtains and uses another person's personal data in some way that involves fraud or deception, typically for economic gain.”<sup>3</sup> Identify theft involves taking another’s identity to conduct a crime. Fraud involves using someone’s personal information to create a false identity. According to the Federal Trade Commission, the top types of reported identify theft and fraud are: government documents or benefits, credit card, phone or utilities, bank, employment, loan, and others such as law enforcement evasion.<sup>3</sup>

In 2012, there were 73,826 reported complaints of fraud in the New York Metropolitan area corresponding to 390 out of 100,000 people. Additionally, there were 23,297 reported complaints of identify theft equivalent to 123 per 100,000 people.<sup>4</sup>

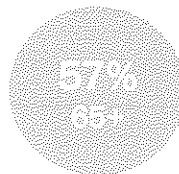
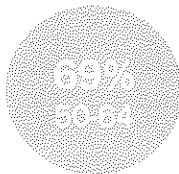
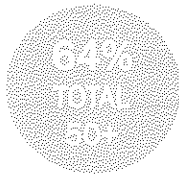
Identity theft, fraud, and scams go hand in hand. In a 2013 AARP poll of NYC voters 50+, over one-third of respondents said either themselves or someone they know has encountered fraud or a “scam” in the past five years. Those under age 65 are just as likely to have encountered fraud or a scam as those over age 65.

Due to confusion, embarrassment, emotional harm or perceived minimal financial loss, many financial scams go unreported. Of 50-64 year olds that have experienced fraud or a scam, nearly seven in 10 have reported this fraud to someone. Comparatively, only 57 percent of the 65+ that reported experiencing fraud actually reported it.<sup>5</sup>



Voter Data

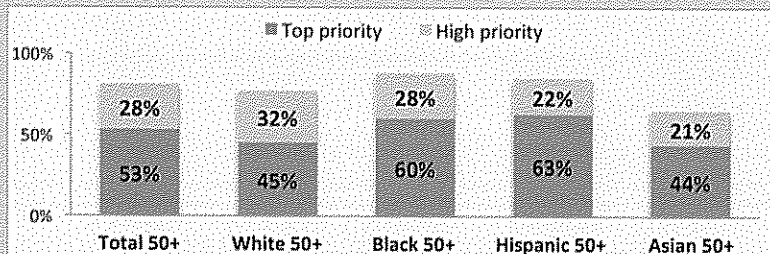
### RATE OF REPORTING FRAUD AMONG 50+ VICTIMS IN NYC<sup>5</sup>



Survey Question:  
To your knowledge, was this incident reported to anyone?

Voter Data

### THE MAJORITY OF NYC VOTERS 50+ SAY PROTECTING CONSUMERS FROM UNFAIR/DECEPTIVE PRACTICES SHOULD BE A TOP OR HIGH PRIORITY<sup>5</sup>



# IDENTITY THEFT IS A MAJOR WORRY OF NYC 50+ VOTERS

## IDENTITY THEFT IS THE TOP FRAUD-RELATED WORRY AMONG ALL RACES AND ETHNICITIES

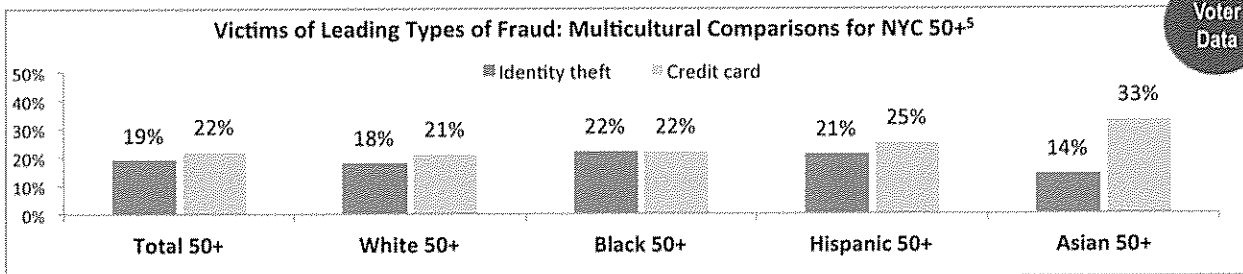
Identity theft is the nation's fastest growing crime.<sup>6</sup> One reason identity theft is so ubiquitous is that it can occur through high-tech or low-tech means. Victims can be scammed online through the use of technology that steals financial and personal information. Victims can also be scammed offline through the loss of a wallet or through personal documents discarded in the trash. In NYC, over one-third of 50+ voters say either they or someone they know have encountered fraud or a "scam" in the past five years and an overwhelming three-fourths are extremely or very worried about being a victim of identity theft.<sup>5</sup>

A multicultural comparison of the types of fraud, unfair, or deceptive practices that are most worrisome reveals that identity theft is the top fraud-related worry for all race/ethnicities and by a fairly wide margin. Hispanics generally present more intense worry than other groups, followed by African Americans.

Voter Data

Extremely/Very Worried About Fraudulent, Unfair or Deceptive Practices: Multicultural Comparison for NYC's 50+ <sup>5</sup>					
	Total 50+	White 50+	Black 50+	Hispanic 50+	Asian 50+
Identity theft	75%	69%	78%	84%	61%
Debt collection	56%	47%	60%	69%	27%
Home financing and home equity loans	53%	44%	58%	64%	30%
Home repairs and home repair financing	52%	44%	55%	64%	33%
Internet loans	49%	41%	54%	60%	34%
Check-cashing outlets	46%	36%	51%	64%	27%
Sweepstakes	41%	32%	44%	58%	27%

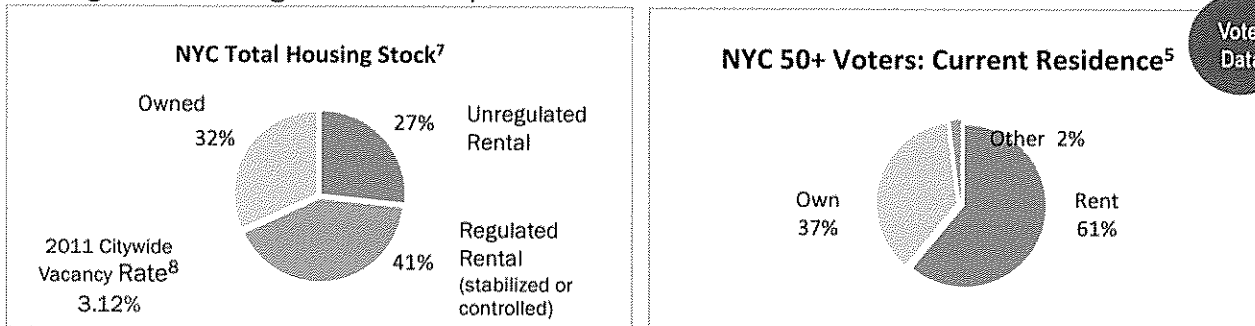
Identity theft or credit card fraud has impacted roughly one-fifth to one-fourth of 50+ voters in NYC. Asians are far more likely to cite credit card fraud (33%) than identity theft (14%).



NEW YORK STATE RANKS 5<sup>TH</sup> IN THE NATION WITH IDENTITY THEFT COMPLAINTS REPORTED IN 2012.<sup>4</sup>

# LACK OF HOUSING AND INCREASES IN STABILIZED RENT THREATEN ECONOMIC SECURITY FOR 50+ NEW YORKERS NYC'S HOUSING MARKET WILL REQUIRE INNOVATIVE SOLUTIONS TO MEET THE NEEDS OF ITS GROWING, CHANGING OLDER POPULATION

Two-thirds of New York City's housing stock is rental properties and of them, the majority is either rent stabilized, rent controlled or part of other regulated rental programs. Similarly, two-thirds of 50+ NYC voters rent their homes, with even larger majorities renting in 3 out of 5 boroughs and among Black and Hispanic resident voters.



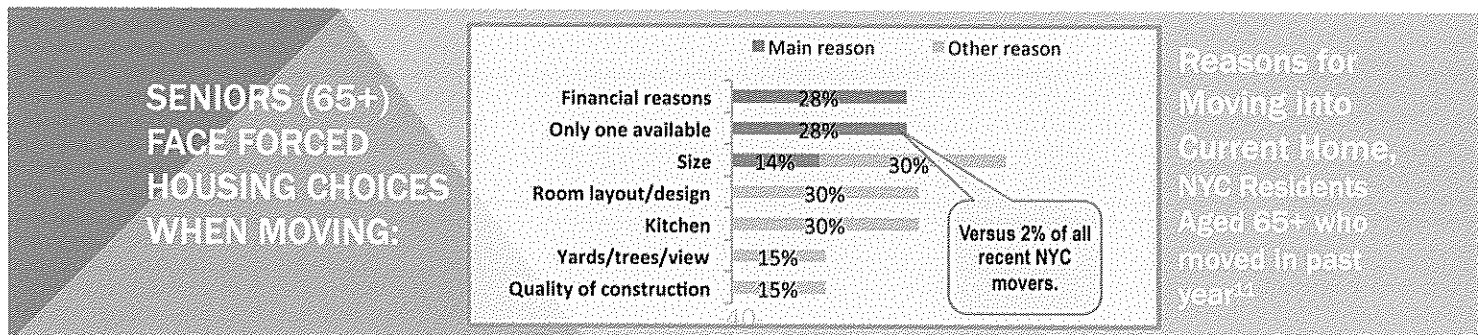
## Rent and Ownership of Current Residence among 50+ NYC Voters<sup>5</sup>:

	Age		Borough				Staten Island	Race/Ethnicity			
	50-64	65+	Bronx	Brooklyn	Manhattan	Queens		White	Black	Hispanic	Asian
Rent	61%	61%	71%	64%	75%	47%	36%	51%	70%	79%	33%
Own	37%	37%	29%	33%	24%	49%	62%	48%	27%	19%	57%

According to the New York City Rent Guidelines Board's 2013 Housing Supply Report, rental housing availability remains tight, with a Citywide vacancy rate of just 3.12% in 2011, and overcrowding remains a problem despite recent housing initiatives to help reduce the affordable housing shortage.<sup>8</sup>

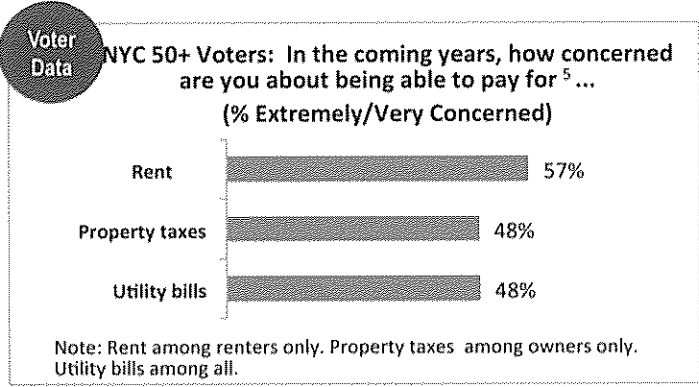
Further, in June 2013 the New York City Rent Guidelines Board voted to raise stabilized rents between 4% and 7.75% beginning October 2013. In their remarks, board members assert that the hike was unavoidable in the face of increasing fees for building owners while acknowledging that it would force some rent-stabilized tenants to choose between paying their rent and paying for basic necessities.<sup>9</sup> As a percentage of income, rate hikes have a significant implication for older adults who rely on fixed incomes below the city average.<sup>10</sup> New and innovative housing ideas are needed to implement a sustainable solution to meet demand and safeguard affordability, particularly for older residents.

## WHEN SENIORS MOVE, THEIR NEW HOME CHOICE IS MOST DETERMINED BY FINANCIAL REASONS AND LACK OF AVAILABILITY

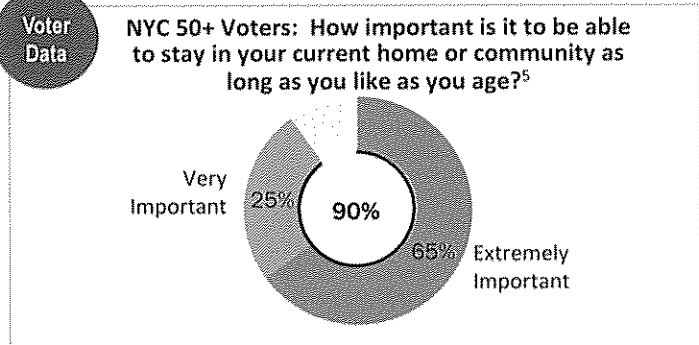


# CONCERN ABOUT BEING ABLE TO AFFORD HOUSING IN THE FUTURE RUNS HIGH AMONG 50+ VOTERS

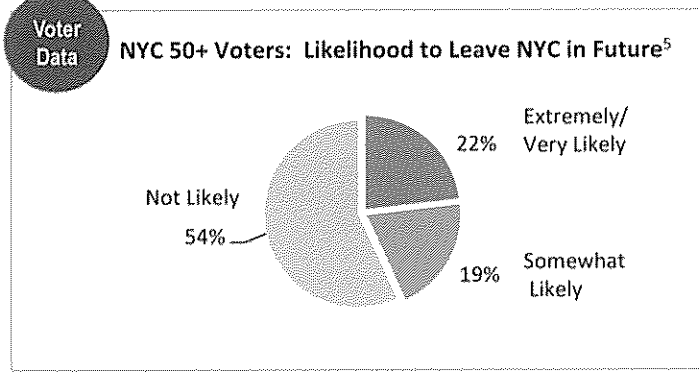
## JUST HALF OF 50+ PLAN TO STAY IN THE CITY



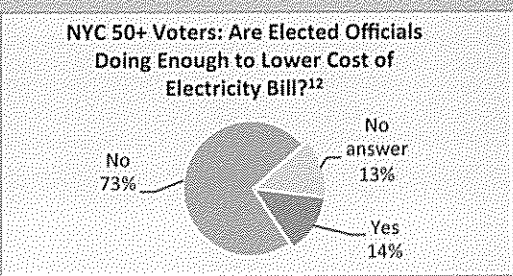
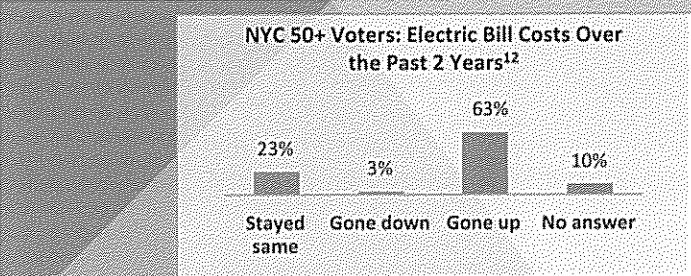
Despite ongoing efforts to alleviate the affordable housing shortage in NYC, the issue continues to provoke anxiety with 50+ voters. Large proportions of renters and owners alike are highly concerned about being able to afford the cost of living in NYC as they age.



50+ voters nearly unanimously agree that aging in one's current home or community is important, yet there is a 50/50 split in the number who plan to stay in NYC and those who are at least somewhat likely to leave the City as they age.



### CONCERN ABOUT FUTURE UTILITY COSTS MAY BE RESULT OF RISING BILLS AND NOT ENOUGH OBSERVED REFORM



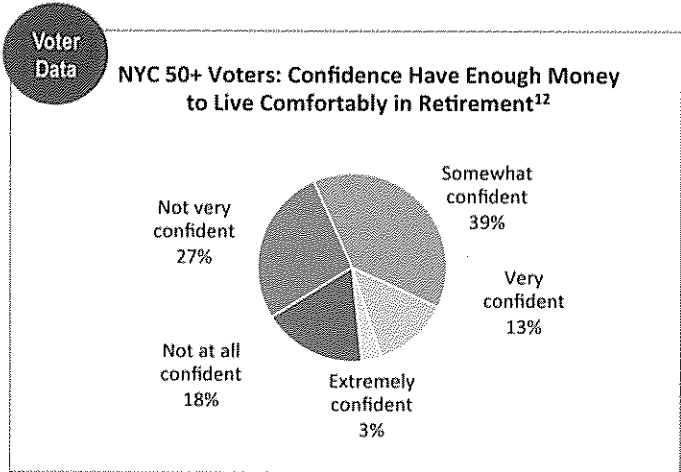
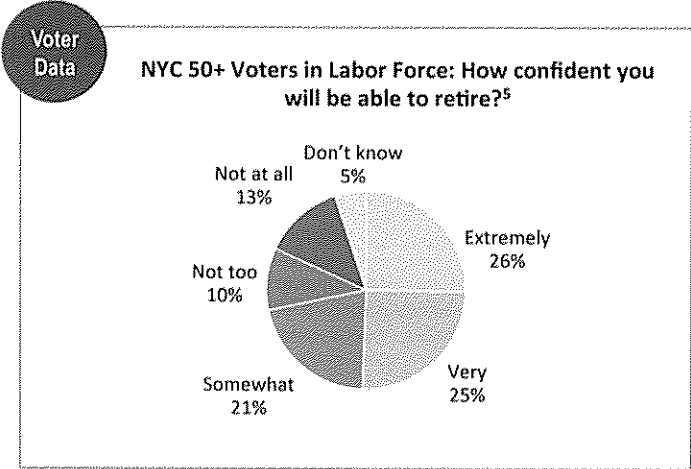
# TRADITIONAL RETIREMENT IS AN ILLUSION FOR MANY 50+ NEW YORKERS

## MANY 50+ CAN'T AFFORD TO RETIRE

A 2012 report on retirement readiness published by the NYC Comptroller's office stated that more than one-third of NYC households in which the head is near retirement age (55-64 years old) have liquid assets of less than \$10,000. It concluded that this cohort of NYC Boomers will either have to subsist almost entirely on Social Security income or will not be able to retire at all.<sup>13</sup>

This acute lack of preparedness for retirement is reflected in 50+ voters' own feelings about their ability to retire. As discussed in Section 3 of this report, only half of 50+ voters in the labor force have strong confidence that they will ever be able to retire.

Furthermore, confidence in "living comfortably" in retirement is an even dimmer possibility suggesting that New Yorkers expect to trade down on their standard of living in order to afford retirement. In a 2012 AARP poll of 50+ NYC voters, only 16% expressed strong positive confidence in having enough money to live comfortably throughout their retirement years while a large majority – 84% – were either "somewhat confident", "not very confident" or "not at all confident" that they would have enough money to do so.<sup>12</sup>



**IN 2009, 49% OF NYC WORKERS AGE 55-64 ("NEAR RETIREMENT AGE") WERE NOT OFFERED AN EMPLOYER-SPONSORED RETIREMENT PLAN<sup>13</sup>**

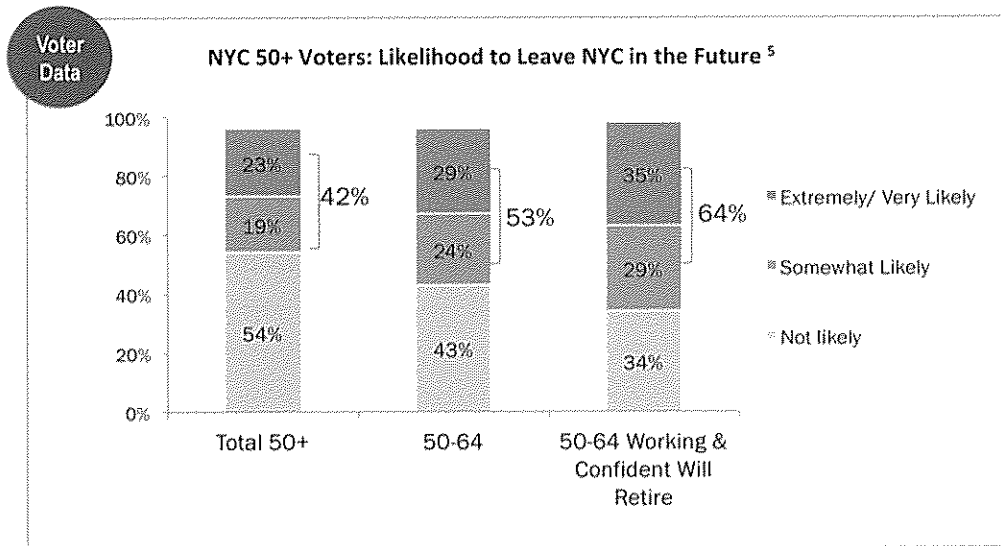
# MIDDLE CLASS BOOMERS WHO CAN RETIRE, PLAN TO LEAVE NYC

## SIX IN TEN WORKING BOOMERS CONFIDENT ABOUT RETIREMENT ARE LIKELY TO LEAVE NYC

In addition to the large portion of NYC Boomers who will not be able to retire, more than one in three of those who are most confident they will retire are extremely to very likely to leave NYC in retirement.<sup>5</sup>

Moreover, there are differences by social class on this question. Pre-retirement 50-64 year olds who self-identify as upper class are least likely to leave NYC in the future compared to their middle and lower class counterparts (53% not likely vs. 39% and 36%, respectively.) The implication is that the upper class can afford to stay; the middle class cannot. For the lower class it may be more difficult to afford leaving even if the desire is there.

If left unchecked, these two dynamics – Boomer retirement flight and plight - can have a compound impact on the City as it prepares for an aging Baby Boomer population, resulting in a loss of future revenue from middle class retirees with retirement resources and leaving those who remain in more polarized social classes.



42% OF ALL 50+ VOTERS AND 53% OF BOOMER VOTERS CONSIDER LEAVING NYC ONCE THEY RETIRE AND AS THEY AGE <sup>5</sup>

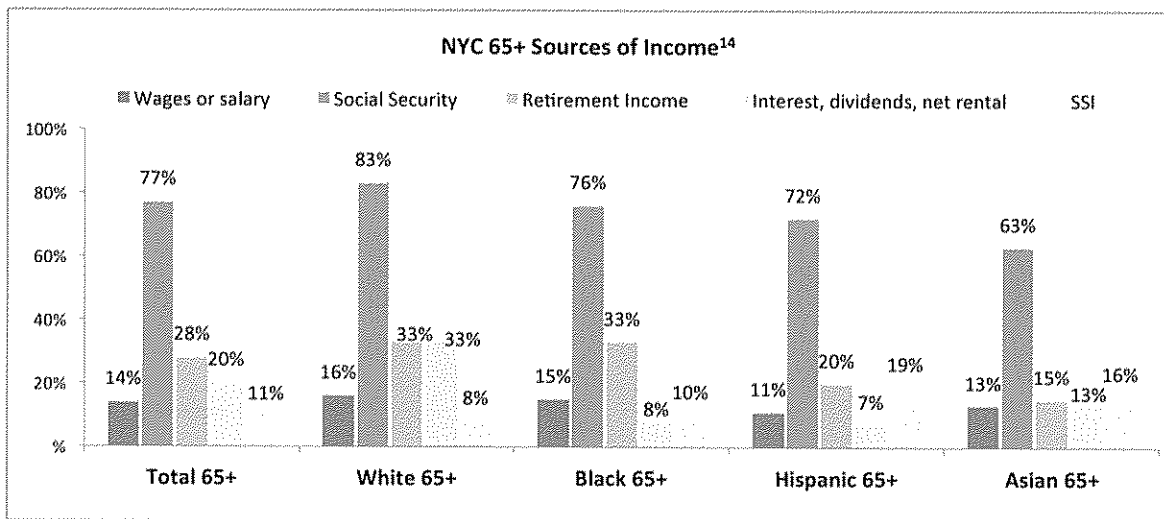
# MORE NYC SENIORS RELY ON SOCIAL SECURITY BENEFITS THAN ANY OTHER SOURCE OF INCOME

## ONLY ONE-FOURTH OF 65+ RECEIVE OTHER RETIREMENT INCOME

Currently, Social Security benefits comprise a large portion of the aggregate household income for Seniors (65+). By age 65, only 14% of all NYC Seniors (65+) earn wages or salary from work and just about one-fourth have retirement income such as pensions or employer-sponsored plans. In contrast, three-fourths of NYC Seniors receive Social Security benefits.<sup>14</sup>

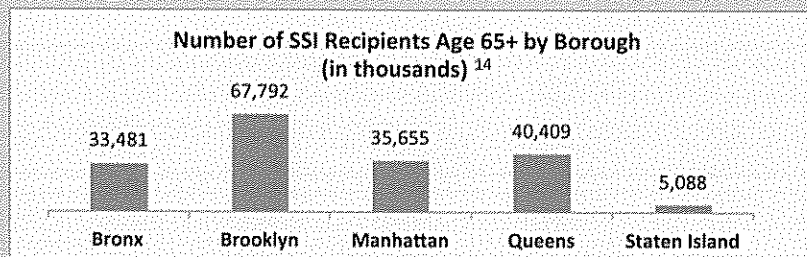
Overall, White Seniors (65+) have more diversified sources of income, with retirement income and investment income each available for one-third. Whites are also most likely to receive Social Security benefits at 83%. Black Seniors are as likely as Whites to have retirement income but lag in investment resources. Comparatively fewer Hispanics and Asians have other sources of income and they are more likely to receive Supplemental Security Income (SSI).<sup>14</sup>

State of the 50+ in NYC 2014



**IN 2012, THE AVERAGE YEARLY SOCIAL SECURITY BENEFIT FOR A NEW YORK STATE RECIPIENT AGE 65 AND OLDER WAS \$15,580.<sup>15</sup>**

**BROOKLYN HAS THE LARGEST NUMBER OF 65+ SSI RECIPIENTS AMONG THE BOROUGHS**



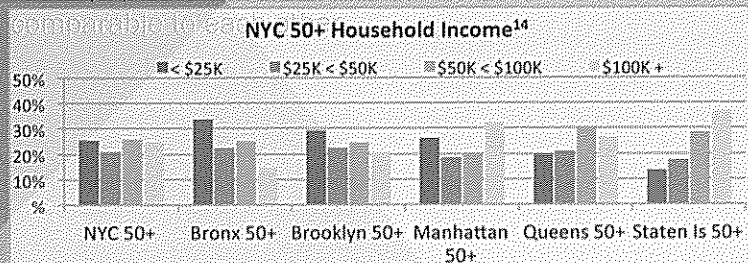
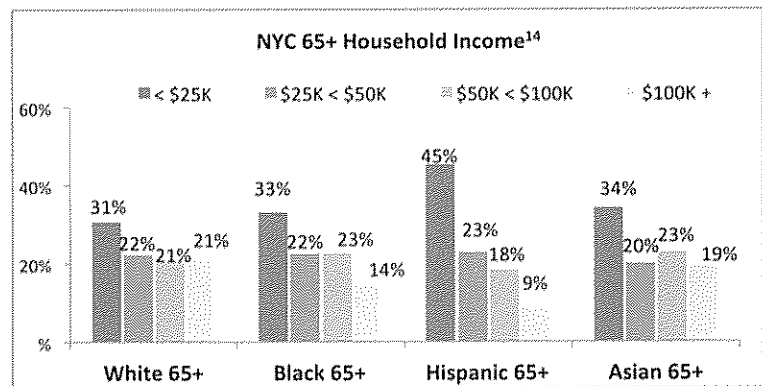
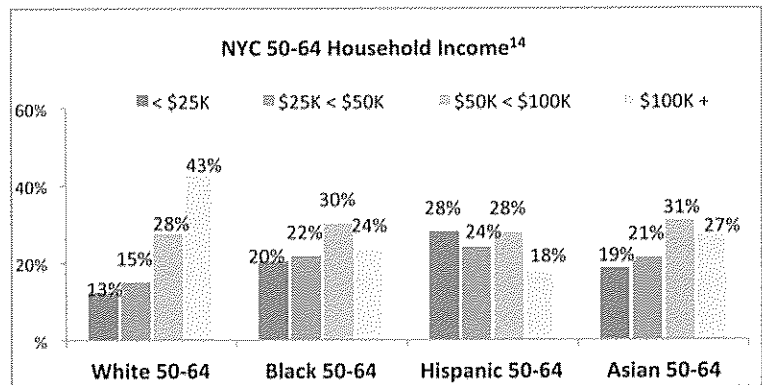
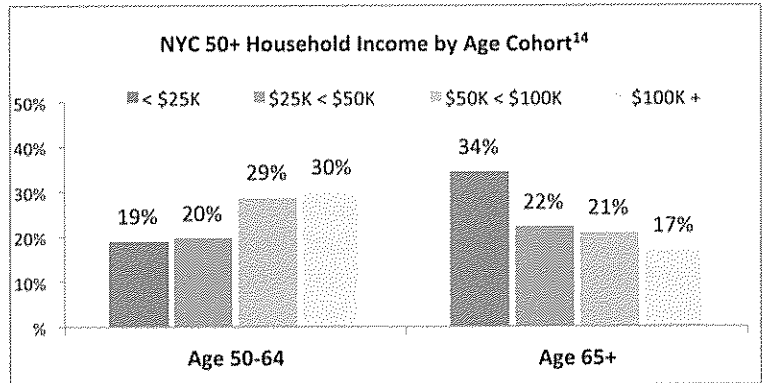
# NYC BOOMER AND SENIOR HOUSEHOLDS HAVE DIVERGENT INCOME DISTRIBUTIONS

## THE LARGEST DISPARITY IN HOUSEHOLD INCOME IS OBSERVED FOR HISPANIC SENIORS

According to the US Census Bureau, range of household income for NYC's 50+ population is rather evenly distributed with roughly one-fourth each under \$25,000, between \$25,000 and \$50,000, between \$50,000 and \$100,000 and \$100,000 or more.<sup>14</sup>

An examination of incomes by age shows Boomer households (age 50-64) are more likely to skew toward the high end of the income range with 30% in six-figure households (\$100K or more). Senior (65+) household incomes predictably skew lower as they tend to have more retirees among them. Senior household income distribution is almost the reverse of their 50-64 year old counterparts – 34% live in households earning less than \$25K per year.

The pattern of comparatively lower incomes among Senior-led households is consistent across all race/ethnicity groups. The greatest contrast in household income distribution is observed between White Boomer (50-64) households where 43% earn \$100K or more per year, and Hispanic Senior (65+) households with 45% under \$25,000 per year. Senior household income distributions for White, Black and Asian populations are more



**BRONX AND BROOKLYN BOROUGHS HAVE THE LARGEST PROPORTION OF 50+ HOUSEHOLDS UNDER \$25K**

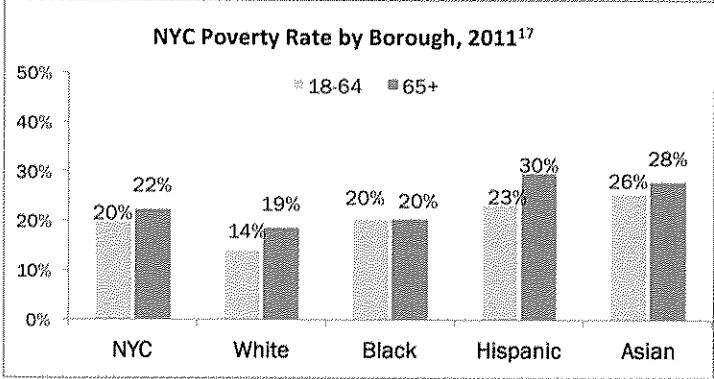


## MANY NYC SENIOR HOUSEHOLDS ARE LIVING IN POVERTY HISPANIC AND ASIAN SENIORS ARE MOST AT RISK

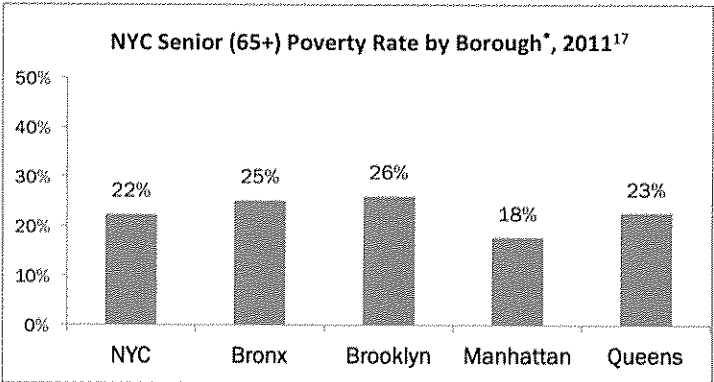
In response to the need for a more geographic-specific measure of poverty for NYC, the NYC Center for Economic Opportunity (CEO) has created an alternative to the official Federal poverty threshold which does not take into account different requirements across the nation to maintain the same standard of living. The CEO's NYC-specific poverty threshold is substantially higher than the official Federal poverty threshold for all household types and so is its estimation of the percent of residents living beneath that threshold.

In 2011, the CEO poverty threshold for a NYC household of four (two adult, two children) was \$30,945 compared to the official threshold of \$22,811 or \$15,785 for a senior (65+) household.<sup>16,17</sup> (Unlike the official Federal measure of poverty, the CEO threshold is not adjusted for householders age 65+.<sup>17</sup>) By its measure, the CEO estimated in 2011 that 21.3% of all NYC households and 22.4% of senior households (age 65+) were in poverty compared to the official measure of 19.3% and 17.5%, respectively.

An examination of CEO poverty rates by age and race reveals that Hispanics and Asians are most at risk of living in poverty in NYC. For Hispanic Seniors (65+), the rate of poverty approaches one in three and is a full seven percentage points higher than the rate among Hispanic adults of traditional "working age" (age 18-64).



In the boroughs, Seniors (65+) in Brooklyn and the Bronx report the highest poverty rate, while Manhattan has the lowest poverty rate.<sup>17</sup> As seen in Chapter 3, rates of Medicaid enrollment are highest in the Bronx and mimic the rate of poverty.

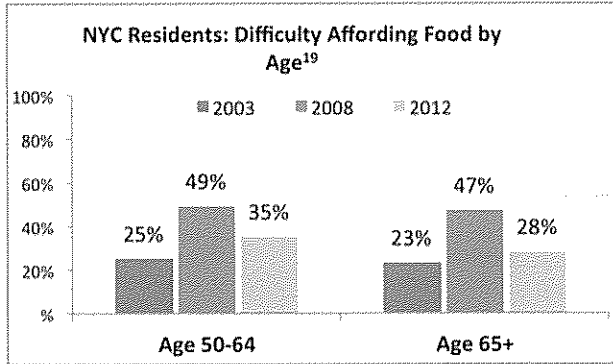


\*Staten Island data not available.

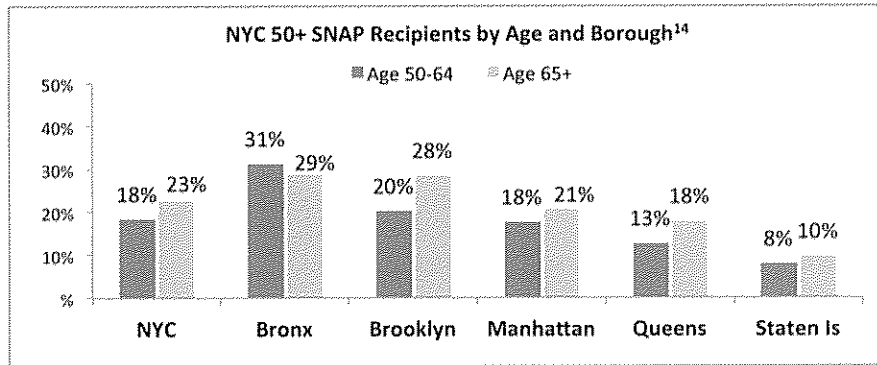
**ONE IN FIVE 65+ NYC HOUSEHOLDS LIVE IN POVERTY<sup>17</sup>**

# ALTHOUGH DOWN FROM POST RECESSION HIGHS, FOOD INSECURITY REMAINS AN ISSUE FOR NYC 50+ BETWEEN 2009 AND 2011, 11 PERCENT OF THE SENIOR POPULATION WERE FOOD INSECURE<sup>18</sup>

Although New York City saw a decrease in the overall difficulty to afford food after stimulus funding and relief measures were in effect (from 40% in 2009 down to 32% in 2012), a sizeable portion of the older population in NYC continues to encounter a problem with hunger.<sup>19</sup>



Over one-third (35%) of the 50-64 age group had trouble affording food in 2012 and expressed likelihood to pay for other expenses over food.<sup>19</sup> When compared to nearly a decade prior, this age group has seen a 40 percent growth in their inability to afford food (25% difficulty in 2003). Moreover, among the 65+, there was an increase from 2011 to 2012 in the percent of residents who say they must decide whether or not to pay for medicine or medical care instead of food (11% to 16%).<sup>19</sup>



One resource intended to combat the hunger problem and lift residents out of poverty in New York City is the national governmental program known as SNAP (Supplemental Nutrition Assistance Program, formerly known as Food Stamps).

According to data reported in the American Community Survey, the proportion of 50+ New Yorkers receiving SNAP benefits citywide from 2009-2011 was far lower than the proportion who had difficulty affording food. Various enrollment barriers keep eligible residents from receiving SNAP benefits, particularly among Seniors (65+). Barriers include: the belief they will only get the minimum benefit; unawareness of eligibility; stigma or embarrassment; and an overwhelming enrollment process. Cultural and language barriers also prevent many Hispanic and Asian seniors from accessing benefits.<sup>20</sup> Across NYC boroughs, most community districts have SNAP under-enrollment for 60+ residents of 45% or more and as high as 91%. This amounts to thousands of NYC 60+ residents who are eligible for SNAP but not-enrolled.<sup>21</sup>

RESIDENTS 60+ EXPERIENCING HUNGER (2009-2011) <sup>18*</sup>			
Borough	Brooklyn	Manhattan	Queens
	21%	11%	10%
	45,671	53,506	27,486
			35,334

\*Staten Island data was not available for 60+

**FOOD INSECURITY OR "HUNGER" OCCURS WHEN FOOD INTAKE IS REDUCED AND EATING PATTERNS RUPTURED BECAUSE THE HOUSEHOLD LACKS MONEY AND RESOURCES FOR FOOD**

#### Section 4: Economic Security Threat References

1. *The Multicultural Economy, 2013*. Selig Center for Economic Growth, Terry College of Business, The University of Georgia, June 2013. <http://www.selig.uga.edu>
2. U.S. Bureau of Labor Statistics. Consumer Expenditure Survey 2011 (Interview and Diary). Integrated survey expenditure tables by PSU and age of the CU reference person prepared by AARP Public Policy Institute.
3. US Department of Justice. <http://www.justice.gov/criminal/fraud/websites/idtheft.html>
4. *Consumer Sentinel Network Data Book for January- December 2012*. Federal Trade Commission. Available at <http://www.ftc.gov/sentinel/reports/sentinel-annual-reports/sentinel-cy2012.pdf>
5. AARP Public Opinion Survey of NYC Registered Voters age 50 and older, June 2013. <http://www.aarp.org/nyc50plus>
6. New York County District Attorney's Office. <http://manhattanda.org/resources-victims-identity-theft/cybercrime>
7. U.S. Census Bureau, 2011 New York City Housing and Vacancy Survey. [http://www.census.gov/housing/nyc/hvs/data/2011/nyc\\_hvs11.html](http://www.census.gov/housing/nyc/hvs/data/2011/nyc_hvs11.html)
8. New York City Rent Guidelines Board, 2013 Housing Supply Report, May 30, 2013. Available at [http://www.housingnyc.com/downloads/research/pdf\\_reports/13HSR.pdf](http://www.housingnyc.com/downloads/research/pdf_reports/13HSR.pdf)
9. New York City Rent Guidelines Board. <http://www.nycrgb.org/html/guidelines/orders/order45.html>. Accessed Oct. 25, 2013. NBC New York news article covering June 20, 2013 board meeting approving rate hike: <http://www.nbcnewyork.com/news/local/NYC-Rent-Stabilized-Apartments-Hike-Approved-Rent-Guidelines-Board-212402621.html>. Accessed October 25, 2013.
10. *Toward an Age-Friendly New York City: A Findings Report*. New York Academy of Medicine. Fall 2008. Available at [http://www.health.ny.gov/diseases/aids/conferences/docs/nyam\\_age\\_friendly\\_report.pdf](http://www.health.ny.gov/diseases/aids/conferences/docs/nyam_age_friendly_report.pdf)
11. U.S. Census Bureau, American Housing Survey, New York City, 2009. Available at <http://www.census.gov/housing/ahs/data/newyork.html>
12. AARP NY Legislative Issue Survey of 50+ Registered Voters in NYC, December 2012.
13. *Are New Yorkers Ready for Retirement? Trends in Plan Sponsorship, Participation, and Preparedness*. New York City Comptroller's Office, Budget & Policy Bureau. Available at <http://comptroller.nyc.com/rsnyc/reports.asp?f=4>
14. U.S. Census Bureau. American Community Survey, PUMS 2009-2011. Prepared by AARP Research
15. OASDI Number and Total Monthly Benefits for Beneficiaries, age 65 or older, 2013: <http://www.ssa.gov/policy/docs/statcomps/supplement/2013/5i.html#table5.i3>
16. U.S. Department of Health and Human Services <http://aspe.hhs.gov/poverty/13poverty.cfm>
17. New York City Center for Economic Opportunity. CEO Poverty Measure, 2005 - 2011. <http://www.nyc.gov/html/ceo/html/poverty/lookup.shtml>. See Appendix B for details on the methodology for deriving a poverty measure for NYC. [http://www.nyc.gov/html/ceo/downloads/pdf/ceo\\_poverty\\_measure\\_2005\\_2011.pdf](http://www.nyc.gov/html/ceo/downloads/pdf/ceo_poverty_measure_2005_2011.pdf)
18. *The Perpetual Storm: Hunger Before and After Hurricane Sandy*. New York City Coalition Against Hunger. Available at [http://www.nyccah.org/files/NYCCAH\\_2012hungerreport.pdf](http://www.nyccah.org/files/NYCCAH_2012hungerreport.pdf)
19. *NYC Hunger Experience 2012: One City, Two Realities*. Food Bank for New York City. [http://www.foodbanknyc.org/files/dmfile/NYCHungerExperience2012\\_FINAL2.PDF](http://www.foodbanknyc.org/files/dmfile/NYCHungerExperience2012_FINAL2.PDF)
20. Seniors and SNAP/Food Stamps. Food Research and Action Center. Available at <http://frac.org/initiatives/addressing-senior-hunger/senior-n-s-and-snap-food-stamps/> Accessed on July 31, 2013.
21. *Preventing Hunger Among the Elderly: Under Enrollment of SNAP by Older New Yorkers*. Council of Senior Centers & Services of NYC, Inc. Available at [http://cscs-ny.org/files/SNAP\\_Benefit\\_Older\\_Adults.pdf](http://cscs-ny.org/files/SNAP_Benefit_Older_Adults.pdf)

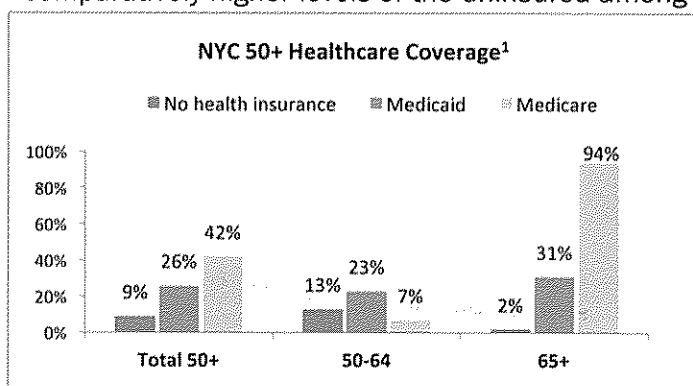
# V. HEALTHCARE

- Insurance Coverage
- Long-term Care
- Caregiving

# MOST NYC 50+ HAVE SOME TYPE OF HEALTH INSURANCE AND MANY RELY ON GOVERNMENT PROGRAMS

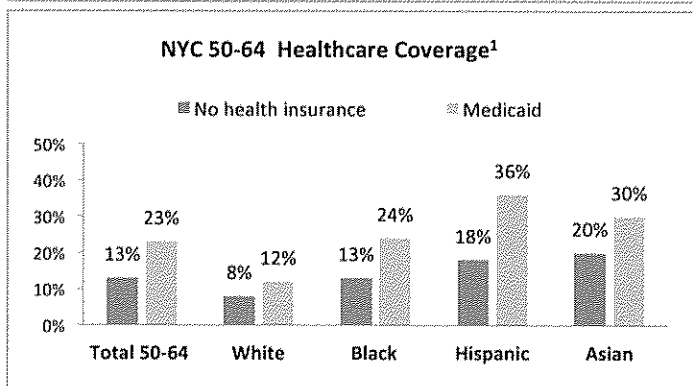
## HOWEVER, LARGER COVERAGE GAPS PERSIST AMONG NON-WHITE 50-64

Overall, about nine in ten New Yorkers ages 50 and older have some type of health insurance.<sup>1</sup> The one in ten 50+ who lack coverage tend to be from the 50 to 64 age cohort, below the common Medicare eligibility age of 65. Looking deeper into racial and ethnic segments reveals comparatively higher levels of the uninsured among non-White adults.

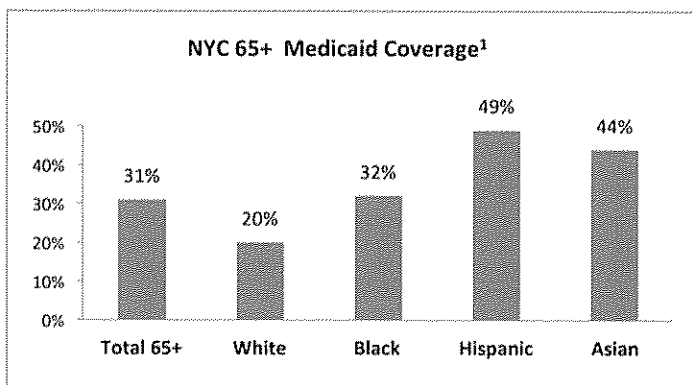


Government programs are significant providers of health care insurance among the City's 50+. The vast majority (94%) of the City's Seniors (65+) receive Medicare. This level of Medicare coverage is consistent across all racial and ethnic segments.

Medicaid is also important to a significant number of low-income older New Yorkers in both the 50-64 and 65+ age cohorts and in fact, Seniors (65+) are more likely to receive Medicaid benefits (31%) than their 50-64 year old counterparts (23%) because 65+ are considered eligible.



Within the 50-64 age group, a substantial proportion of Hispanics and Asians rely on Medicaid for healthcare coverage (36% and 30% respectively). These two groups are also most likely to lack any insurance - about 20% each versus 13% among Blacks and 8% among Whites.



As mentioned above, Medicaid is a significant provider of healthcare coverage for NYC's 65+ (in addition to Medicare) and especially for multicultural seniors. Nearly half (49%) of Hispanic seniors, 44% of Asian seniors and 32% of Black seniors participate in Medicaid, which is a state- and federally-funded program.

State of the 50+ in NYC 2014

20%

**OF NYC ASIANS 50-64 YEARS OLD LACK HEALTH INSURANCE - HIGHER THAN ANY OTHER RACIAL OR ETHNIC GROUP**

*Note: All data and discussion of healthcare coverage in this report is prior to the full implementation of the Affordable Care Act.*

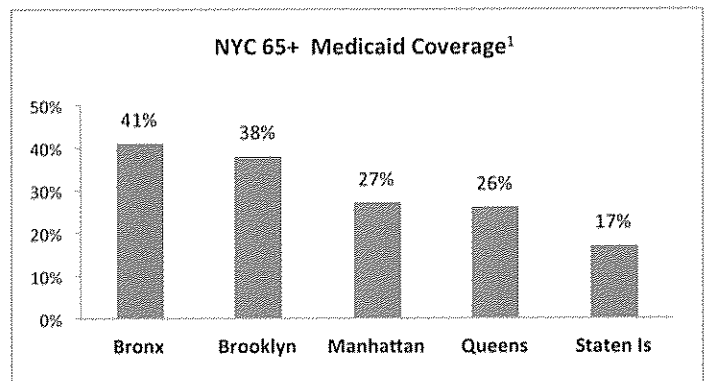
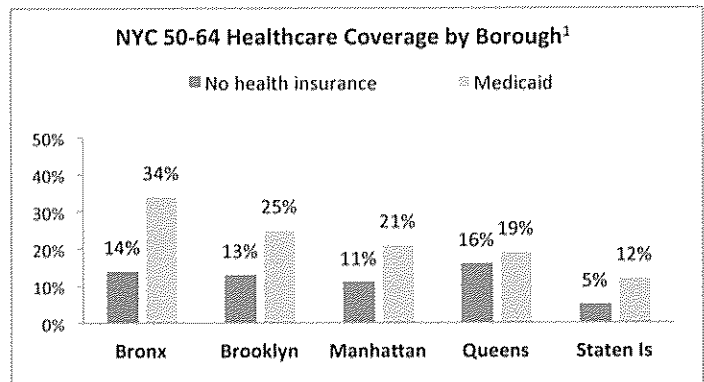
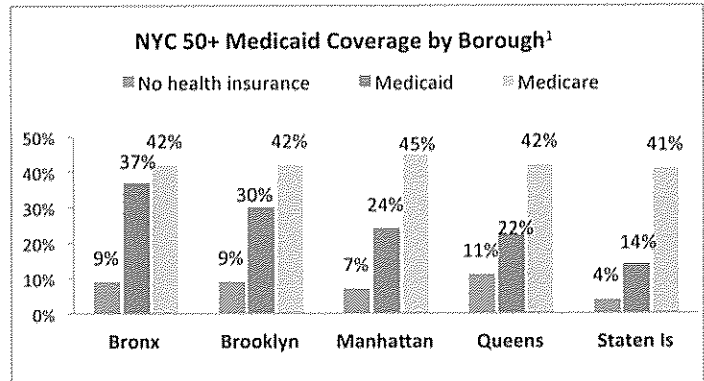
# THE BRONX HAS THE MOST 50+ MEDICAID PARTICIPANTS UNINSURED ADULTS ARE MORE COMMON IN QUEENS

Differences in health coverage across the boroughs are similar to observations by race and ethnicity, reflecting the population concentrations.

The Bronx is the most diverse of the five boroughs, with a 50+ population that is 44% Hispanic, 31% Black and just 19% White - the lowest White representation in the City. Here, 37% of 50+ adults receive healthcare coverage via Medicaid, more than any other borough. By age, this translates into 34% of 50-64 year olds in the Bronx and four in ten seniors receiving Medicaid healthcare.

The larger representation of Asian and foreign-born residents in Queens may account for slightly higher levels of uninsured adults compared to other boroughs. Eleven percent of all 50+ and 16% of 50-64 year olds in Queens are without insurance.

Variation in Medicaid coverage may be partly explained by eligibility criteria set at the federal and state level, including household type, income and citizenship status. For instance, 50+ household income skews lower in the Bronx compared to other boroughs, with 33% reporting less than \$25,000 per year. (See Chapter 4 for more details on 50+ household income data.)



State of the 50+ in NYC 2014

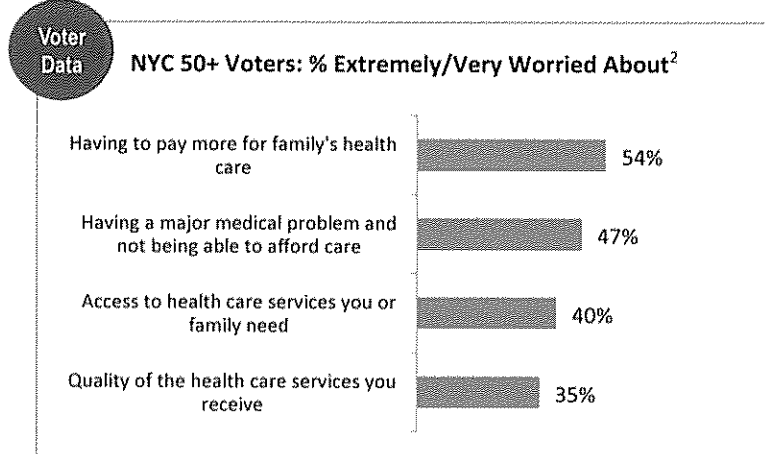
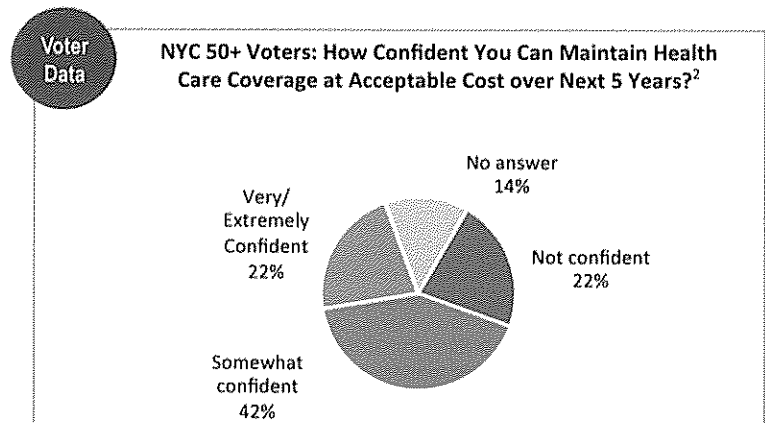
ACROSS THE BOROUGHS, LEVELS OF MEDICAID PARTICIPATION AMONG 50+ ADULTS RANGE FROM A HIGH OF 37% (THE BRONX) TO A LOW OF 14% (STATEN ISLAND)

## 50+ VOTER WORRY ABOUT HEALTHCARE AFFORDABILITY SURPASSES ACCESS OR QUALITY CONCERNS VOTERS LACK CONFIDENCE ABOUT FUTURE COSTS

Affordability of healthcare, and more specifically the uncertainty around future healthcare costs, is a very worrisome concern for many 50+ voters. The unknown effect of the Affordable Care Act may account for part of the uncertainty on the part of voters because there is still much to be learned with regard to containing costs and providing affordable options for families. Thus, the total measure of the law's impact won't be known until it is fully implemented.

Only one-fifth (22%) of 50+ voters are very to extremely confident they can maintain their current coverage at an acceptable cost over the next 5 years. The largest proportion (42%) are somewhat confident and another fifth (22%) are not confident.

Among healthcare-related concerns, having to pay more for the family's healthcare ranks first as the most common worry among 50+ voters (54%) followed by not being able to afford the care needed for a major medical problem (47%). Four in ten worry about their access to services and one-third (35%) worry about the quality of health care services.



### MANY ARE UNCERTAIN AND WORRIED ABOUT THE FUTURE OF HEALTH CARE COSTS FOR THEIR FAMILIES

**64%**  
UNCERTAIN

A MAJORITY OF 50+ VOTERS DO NOT FEEL CONFIDENT ABOUT THE FUTURE COST OF THEIR HEALTHCARE

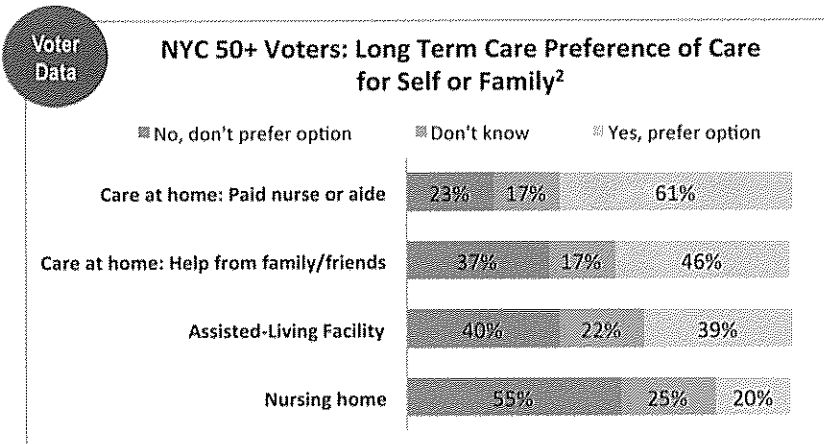
**54%**  
WORRIED

MORE THAN HALF OF 50+ VOTERS ARE WORRIED ABOUT HAVING TO PAY MORE

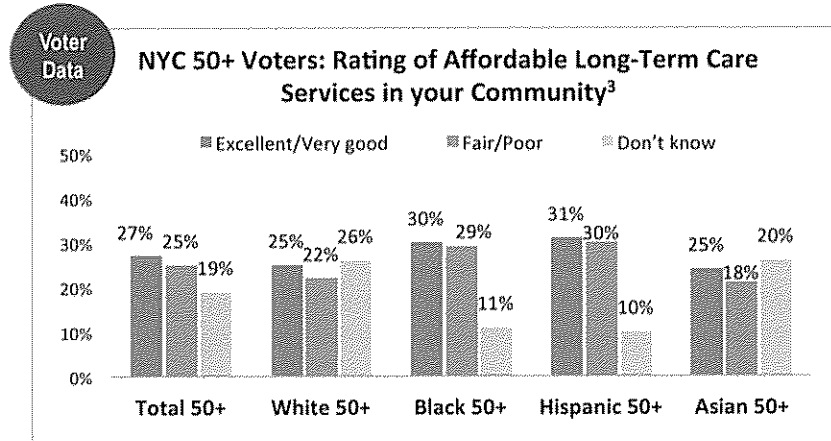
# NYC WILL NEED TO BUILD CAPACITY IN LONG-TERM CARE SERVICES TO FULFILL AGING PREFERENCES

## A MAJORITY OF 50+ NYC VOTERS PREFER TO RECEIVE LONG TERM CARE AT HOME; YET THERE IS A LAG IN AFFORDABLE SERVICES

The National Clearinghouse for Long-Term Care Information defines long-term care as “a range of services and supports needed to meet health or personal needs over a long period of time. Most long-term care is not medical care, but rather assistance with the basic personal tasks of everyday life”.<sup>4</sup> Furthermore, it is estimated that about 70% of the 65+ will need some type of long-term care in their lifetime.<sup>4</sup> Given the projected growth of NYC’s Senior population over the next two decades (40% increase from 2010 to 2030), it is of great importance that the City’s healthcare field be prepared to meet this growing need with affordable long-term care options.



If long-term care services are needed, the top preference among 50+ voters is to receive that care at home by a paid nurse (61%). The second most commonly preferred way to receive long term care is also at home, but with family and friends providing the care.



Only 27% of all NYC 50+ voters rate affordable long-term care services in their community as “Excellent” or “Very good”. Black and Hispanic voters appear to have more familiarity with these services (significantly fewer saying they “don’t know”), yet there are equal proportions giving good and bad ratings in each group.

**BLACK AND HISPANIC 50+ VOTERS IN NYC ARE MORE FAMILIAR BUT NOT MORE POSITIVE ABOUT LONG TERM CARE SERVICES IN THEIR COMMUNITY<sup>3</sup>**



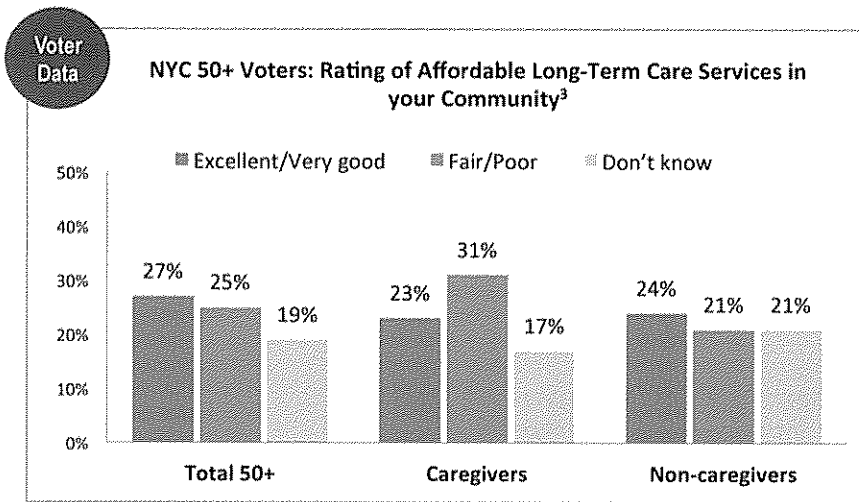
# COSTS OF LONG-TERM CARE THREATEN ECONOMIC SECURITY OF OLDER ADULTS AND THEIR FAMILIES

## COSTS ARE NOT COVERED BY HEALTH INSURANCE OR MEDICARE

Long-term care services and supports are not covered by traditional medical health plans or Medicare. Most long-term care costs are the responsibility of the patient and are direct out-of-pocket expenses.

Average costs in New York City for two years of long-term care range from \$59,000 for home health care (based on 5 visits per week, 6 hours per visit) to \$142,000 for Assisted Living and \$322,000 for Nursing care.<sup>5</sup> Of these options, home health care is both lowest cost and most preferred by 50+ voters to enable independent living at home. Yet, even at the relative bargain of one-fifth the cost of Nursing Home care, the average cost for two years of home health care is more than a full year of household income for most 65+ residents. (57% live in households with incomes of less than \$50,000.)

State of the 50+ in NYC 2014



Some of the people most familiar with long-term care services in their community are the caregivers that provide care for others. Among NYC 50+ voters that have been caregivers within the past 5 years, nearly one-third rate their community's affordable long-term care services as "fair" or "poor" – significantly more than non-caregivers and the total 50+ overall.

## LONG-TERM CARE SUPPORTS AT HOME ARE RELATIVELY LESS EXPENSIVE, BUT STILL UNAFFORDABLE FOR INDIVIDUAL FAMILIES

AVERAGE COST OF CARE IN NEW YORK CITY FOR 2 YEARS <sup>5</sup>

**\$59K**  
HOME HEALTH

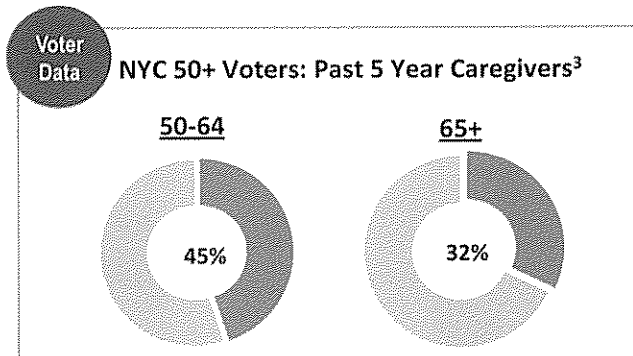
**\$142K**  
ASSISTED LIVING

**\$322K**  
NURSING HOME

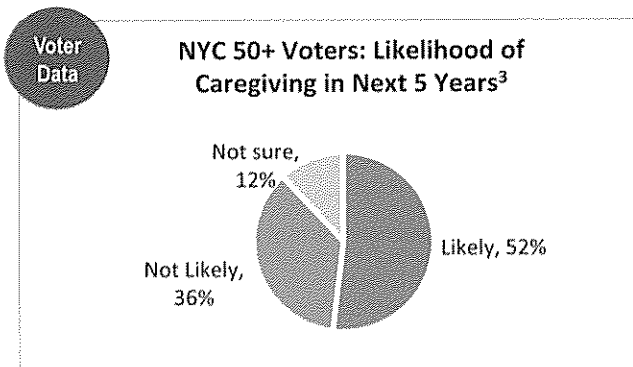
# NYC COMMUNITIES RELY ON FAMILY CAREGIVERS TO PROVIDE UNPAID CARE AND SUPPORT

## THE CONTRIBUTIONS OF FAMILY CAREGIVERS IS A SUBSTANTIAL COST SAVINGS TO THE CITY'S HEALTH CARE SYSTEM

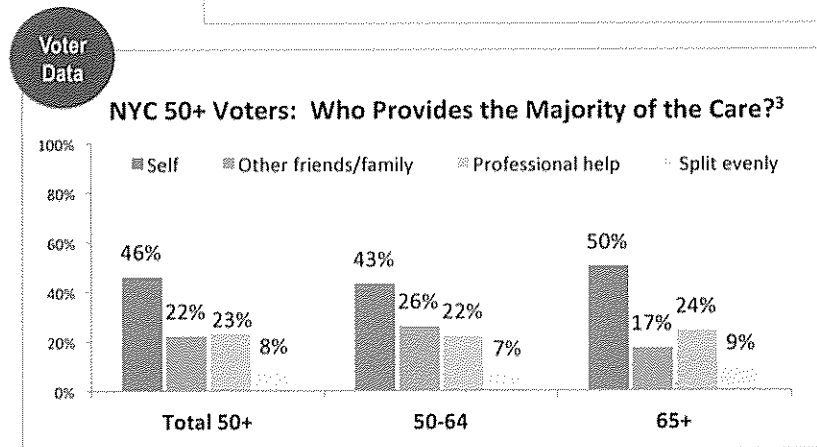
It is quite common for 50+ adults to give unpaid caregiving support to family members and friends. Among all NYC 50+ voters, 39% have been caregivers in the past five years or currently are providing care to a friend or family member. Adults 50-64 years old are significantly more likely than their 65+ counterparts to identify as caregivers (45% vs. 32%).



Moreover, looking ahead over the next five years, NYC voters 50+ do not see their caregiving responsibilities diminishing. More than half (52%) believe they are likely to provide care within the next 5 years and an additional 12% are not sure.



Nearly half of all 50+ caregivers are the primary caregiver. Of note, while seniors (65+) are less likely than their younger counterparts (50-64) to be caregivers, when they are caring for loved ones it is more often as the primary caregiver (50% vs. 43%).

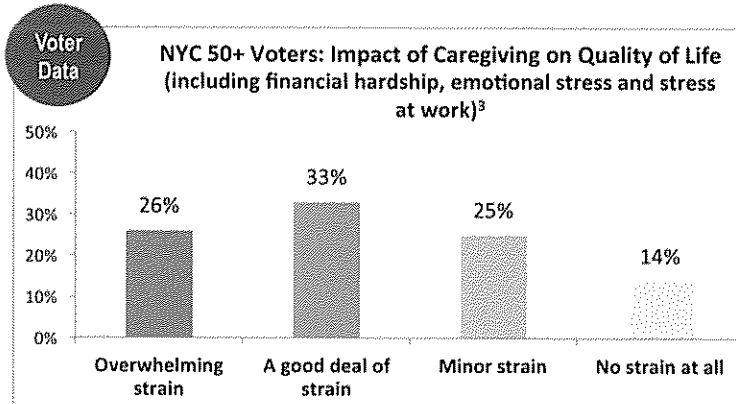


NY STATE HAS 4.1 MILLION CAREGIVERS PROVIDING UNPAID CARE AT ANY GIVEN TIME, PROVIDING 2.68 MILLION HOURS OF CARE VALUED AT \$3.2 BILLION<sup>6</sup>

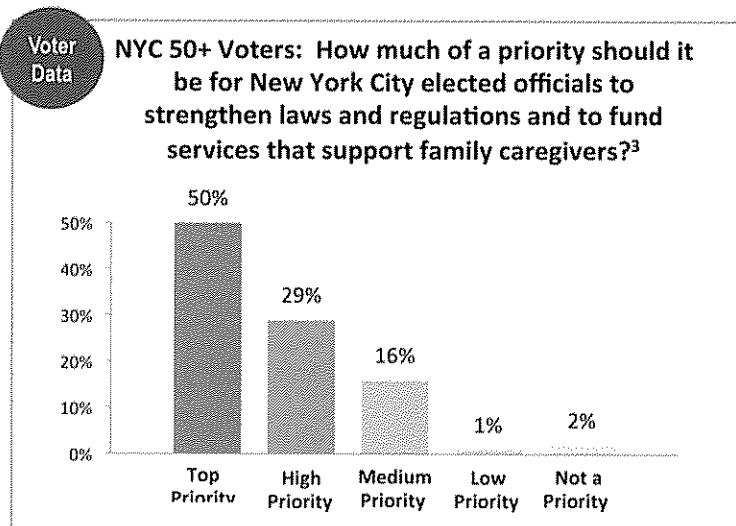
# CAREGIVING RESPONSIBILITIES ARE STRAINING LIVES OF 50+ NEW YORKERS

## 50+ VOTERS WANT ELECTED OFFICIALS TO SUPPORT FAMILY CAREGIVERS

State of the 50+ in NYC 2014



When asked about the extent to which providing care puts a strain on their overall quality of life, nearly six out of ten (59%) 50+ caregivers experience an overwhelming or a good deal of strain. 50+ Hispanic caregivers in NYC are even more likely to report an “overwhelming” level of strain from family caregiving responsibilities (36% versus 23% among Whites).



Given the impact of providing unpaid care on caregivers’ quality of life, most 50+ voters (79%) believe supporting family caregivers should be a priority for NYC elected officials. Black and Hispanic 50+ voters are even more strongly in agreement that caregiver supports by elected officials should be a priority, with nearly nine in ten ranking it top or high (87% and 86%, respectively compared to 73% of Whites.)

## 50+ CAREGIVER PROFILE IN NYC:

59%  
FEMALE

60%  
50-64

41%  
WORKING

25%  
EMPLOYED  
FULL TIME

NEW YORK CITY CAREGIVERS, LIKE MOST IN THE NATION, ARE MORE OFTEN FEMALE THAN MALE. MORE ARE YOUNGER THAN 65 AND TEND TO BE WORKING<sup>3</sup>

**Section 5: Healthcare References**

1. U.S. Census Bureau. American Community Survey, PUMS 2009-2011. Prepared by AARP Research
2. AARP NY Legislative Issue Survey of 50+ Registered Voters in NYC, December 2012.
3. AARP Public Opinion Survey of NYC Registered Voters age 50 and older, June 2013. <http://www.aarp.org/nyc50plus>
4. Administration for Community Living, an agency of the U.S. Department of Health and Human Services. Available at <http://longtermcare.gov/the-basics/who-needs-care/>
5. Federal Long-Term Care Insurance Program Costs of Care. Available at <https://www.ltcfed.com>. Accessed on November 1, 2013.
6. *Valuing the Invaluable: 2011 Update. The Growing Contributions and Costs of Family Caregiving.* The AARP Public Policy Institute. Available at <http://www.aarp.org/relationships/caregiving/info-07-2011/valuing-the-invaluable.html> Accessed on November 1, 2013.
7. The Urban Institute Health Policy Center, Health Insurance Reform Simulation Model, January 2013. Available at <http://www.urban.org/UploadedPDF/412534-Affordable-Care-Act-in-New-York-State.pdf> Accessed on November 21, 2013.

**NUMBER OF NYC ADULTS (4 BOROUGHES) AGES 45-64  
ESTIMATED TO GAIN INSURANCE COVERAGE WITH FULL  
IMPLEMENTATION OF THE AFFORDABLE CARE ACT<sup>7</sup>**

**125K**

# VI. LIVABLE COMMUNITY

- Livability
- Transportation & Pedestrian Safety
- Aging in Place
- Age Friendly Community

# MORE VOTERS CONSIDER NYC'S LACK OF AFFORDABLE HOUSING TO BE A MAJOR PROBLEM, SURPASSING OTHER COMMUNITY CONCERNS

## AFFORDABLE HOUSING IS A KEY VOTING ISSUE FOR NYC 50+

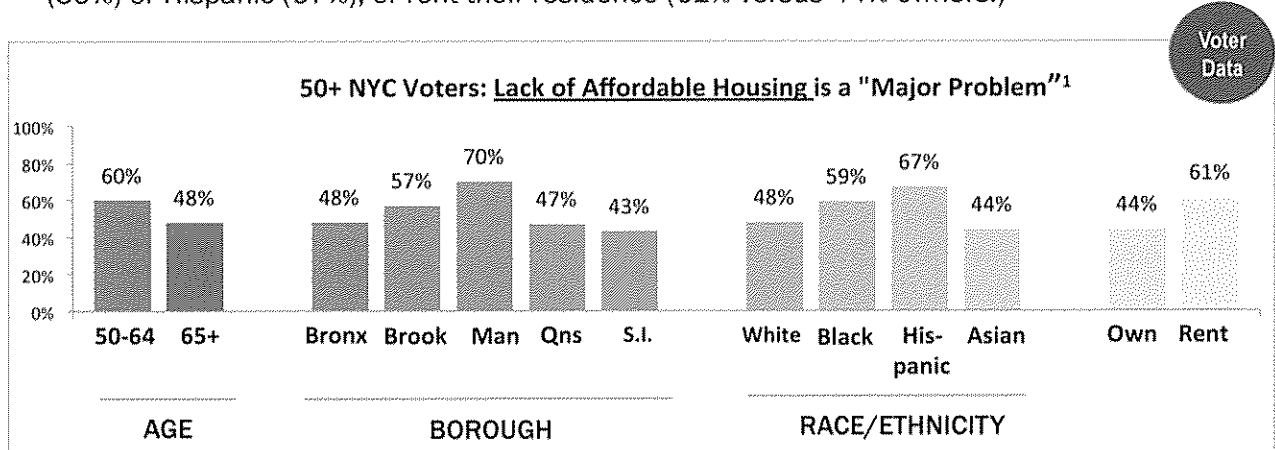
Half of all 50+ NYC registered voters cite lack of affordable housing as a "major" concern, compared to 42% saying heavy traffic and 33% classifying crime as an equally serious problem.

**50+ NYC Voters saying each is a "Major Problem"<sup>1</sup>**



**Survey Question:**  
Is [INSERT] a major problem, minor problem or not a problem at all in your community?

Compared to their counterparts, lack of affordable housing is considered to be a major problem by larger proportions of resident voters who are 50-64 years old (60% versus 48% 65+ years); live in Brooklyn or Manhattan boroughs (57% and 70%, respectively); are Black (59%) or Hispanic (67%); or rent their residence (61% versus 44% owners.)

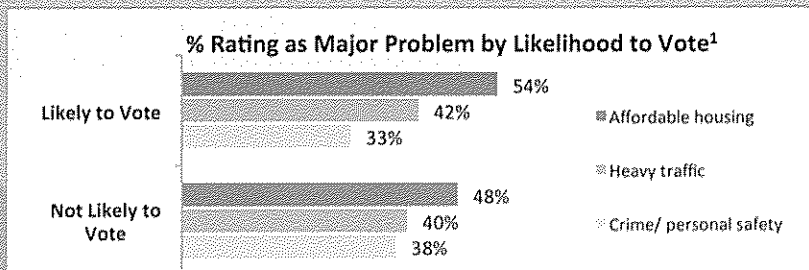


State of the 50+ in NYC 2014

Affordable housing ranks first in major problem ratings among total registered voters; and among the most engaged voters it stands out more clearly as the top regarded "major problem" of the city issues in an AARP survey of 50+ registered voters in NYC.

### HOUSING PROBLEM RANKS FIRST WITH TOTAL VOTERS AND ...

**... BY A WIDER MARGIN AMONG MOST LIKELY VOTERS**

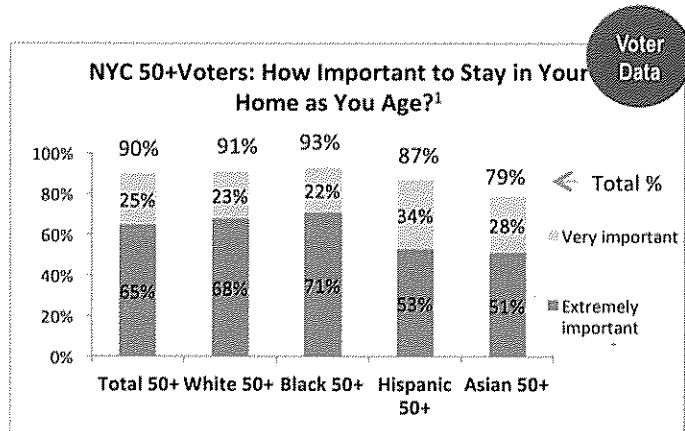


# 50+ VOTERS IN NYC WANT TO STAY IN THEIR OWN HOMES AS THEY AGE

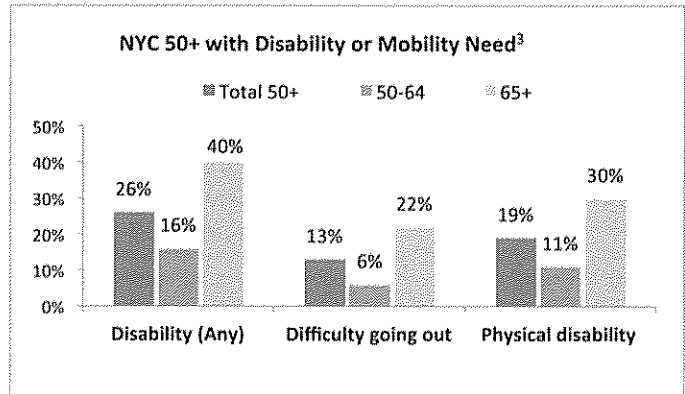
## “AGING IN PLACE” REQUIRES ACCESSIBILITY FOR ALL MOBILITY LEVELS

“Aging in place” is the ability to live in one’s own home and community safely, independently, and comfortably, regardless of age, income, or ability level.<sup>2</sup> Older New Yorkers are no different from older Americans nationally in their near universal preference to stay in their own homes as they age. Ninety percent of 50+ voters in NYC say it is very to extremely important to be able to stay in their homes as they age.<sup>1</sup>

Although a vast majority of all race and ethnic groups consider aging in place important, cultural differences may contribute to slightly lower intensity among Hispanics and Asians. In these ethnic communities it is more commonly expected that elders will eventually move into adult children’s homes or return to a home country of heritage.



One-fourth of all NYC residents age 50+ are living with a disability. Between ages 50-64 and 65+, disability rates more than double, rising from 16% to 40%. Among NYC Seniors (65+), nearly one-third have a physical disability and 22% have difficulty going out of their homes. As the Senior (65+) population grows, it will be important to more people that the City is prepared to address the needs of disabled or mobility challenged residents living in its boroughs.



## HOUSING DESIGNED FOR PHYSICAL AND MOBILE DISABILITIES WILL BECOME INCREASINGLY IMPORTANT.

**DISABILITY AMONG SENIORS (65+) IS MOST COMMON IN THE BRONX (48%) FOLLOWED BY BROOKLYN (43%)**

Disability & Mobility Needs, NYC Seniors (Age 65+) <sup>3</sup>	Bronx	Brooklyn	Manhattan	Queens	Staten Is
Disability	48%	43%	36%	38%	36%
Difficulty going out	26%	26%	19%	21%	21%
Physical difficulty	36%	32%	27%	28%	26%
Hearing difficulty	14%	12%	10%	11%	12%
Vision difficulty	13%	11%	7%	8%	5%

# ALTERNATIVE TRANSPORTATION SERVICES IN NYC COMMUNITIES SHOW ROOM FOR IMPROVEMENT

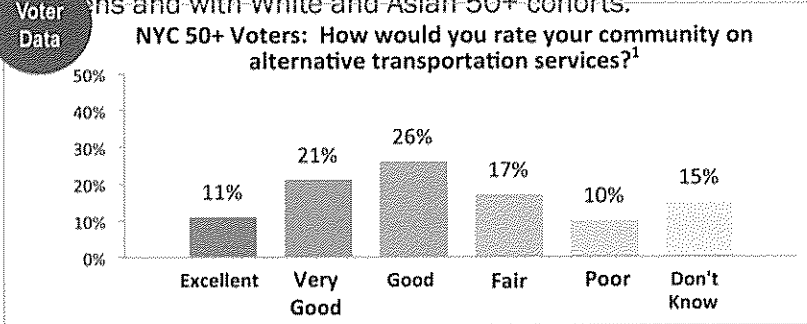
## OVERALL OPINIONS ARE MIXED, SOMEWHAT MORE POSITIVE IN THE BRONX

In its report on aging in place, the AARP Public Policy Institute and the National Conference of State Legislatures identified several livability practices that improve age-friendliness in states and communities and increase the ability of residents to stay in their homes as they age. Beyond affordable and accessible age-friendly housing to decrease the need for institutional care, considerations for community transportation and pedestrian mobility are also important.<sup>2</sup>

An AARP survey in June 2013 found 53% of 50+ NYC voters rate alternative transportation services in their community as good to poor and another 15% weren't able to provide a rating for lack of awareness or experience. One-third consider these services excellent to very good. Bronx residents and Seniors (age 65+) are more likely to give positive ratings to alternative transportation services in their community.

Opinions of alternative transportation services by race and ethnicity are more mixed. Roughly one-third of Black and Hispanic 50+ voters give fair to poor ratings. But among Blacks, slightly more give high ratings of very good to excellent. Awareness or experience (indicated through don't know responses) of alternative transportation options is lowest in Manhattan and Seniors and with White and Asian 50+ cohorts.

**Voter Data**



**Survey Question:**  
How would you rate your community on alternative transportation services, such as community vans, service shuttles and volunteer drivers that help residents maintain their independence as they age?

	Bronx	Brooklyn	Manhattan	Queens	Staten Island	50-64	65+	White 50+	Black 50+	Hispanic 50+	Asian 50+
Excellent/Very Good	37%	30%	28%	32%	27%	28%	35%	31%	36%	29%	29%
Good	28%	25%	25%	26%	27%	26%	26%	25%	24%	30%	27%
Fair/Poor	26%	31%	25%	26%	28%	29%	25%	23%	32%	31%	24%
Don't know	9%	13%	20%	15%	19%	16%	13%	21%	7%	9%	18%

State of the 50+ in NYC 2014

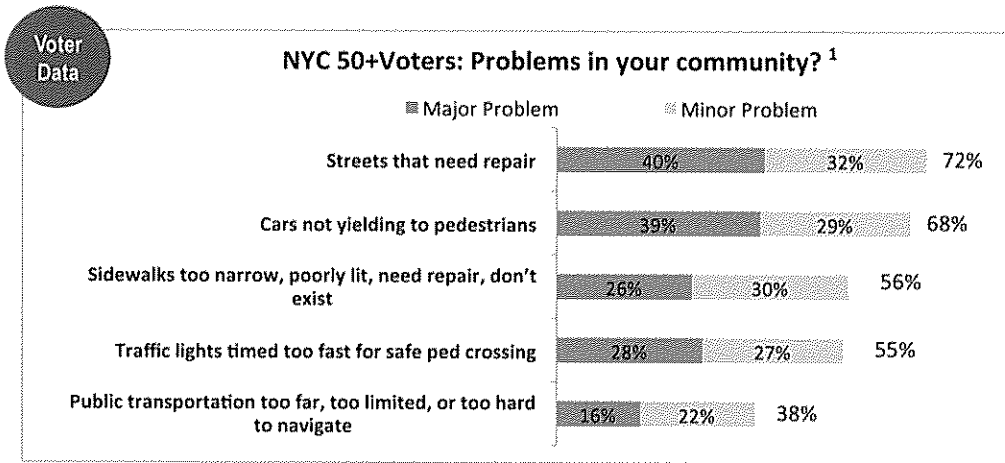
IN 2014, AN ESTIMATED AVERAGE OF 846,000 RIDERS PER MONTH ARE EXPECTED TO BE CARRIED BY NYC'S PARATRANSIT SERVICE, ACCESS-A-RIDE<sup>4</sup>



# PEDESTRIAN SAFETY REMAINS AN AREA OF OPPORTUNITY FOR NYC AGE-FRIENDLY LIVING

## PEDESTRIAN SAFETY STANDS OUT AS A MAJOR PROBLEM FOR 50+ HISPANICS

Thirty-six percent of NYC traffic fatalities are Senior pedestrians – three times their representation in the total citywide population. Since launching the Safe Streets for Seniors program five years ago, NYC has reduced its senior pedestrian fatality rate by 19%.<sup>5</sup> However, a majority of 50+ voters still identify pedestrian safety issues in their community to be a problem.



**Survey Question:**  
Is [INSERT] a major problem, minor problem or not a problem at all in your community?

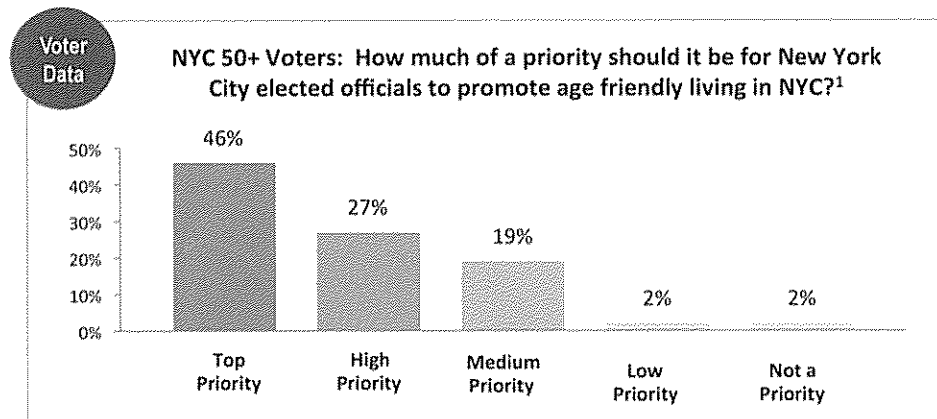
Hispanic adults age 50+ are even more likely than those in other racial or ethnic groups to categorize pedestrian safety as a major problem. More than half of Hispanics 50+ (53%) consider cars not yielding to pedestrians to be a "major" problem in their community, four in ten feel lights are timed too fast for safe crossing and nearly as many (37%) observe major problems with sidewalks. Pedestrian safety strategies in NYC need to include cultural considerations.

% Rating as "Major Problem" in Community, NYC 50+ Voters <sup>1</sup>	White 50+	Black 50+	Hispanic 50+	Asian 50+
Streets that need repair	36%	42%	45%	32%
Cars not yielding to pedestrians	35%	39%	53%	36%
Sidewalks that are too narrow, poorly lit, need repair or don't exist	20%	30%	37%	26%
Traffic lights timed too fast for safe pedestrian crossing	23%	29%	40%	30%
Public transportation is too far, too limited or too hard to navigate	15%	15%	20%	17%
Crime or personal safety	23%	38%	48%	43%

**DIFFERENCES IN RACIAL AND ETHNIC PERCEPTIONS ABOUT PEDESTRIAN SAFETY MIRROR DIFFERENCES IN ACTUAL FATALITIES. NATIONALLY, OLDER ADULTS AND NON-WHITE POPULATIONS HAVE THE HIGHEST PEDESTRIAN DEATH RATES<sup>6</sup>**

# MAJORITY OF 50+ VOTERS THINK NYC ELECTED OFFICIALS SHOULD PROMOTE NYC AGE FRIENDLY LIVING NEARLY HALF CONSIDER IT A TOP PRIORITY

In preparation for the dramatic growth of the City's older population, the Mayor's Office first undertook the Age-Friendly NYC initiative in 2008, becoming certified by the World Health Organization as an Age-Friendly City in 2010. NYC has been a leader in creating age-friendly cities and a model for other communities.<sup>7</sup> A majority of NYC 50+ voters (73%) believe it should still be a top priority or high priority for elected officials.



## Section 6: Livable Community References

1. AARP Public Opinion Survey of NYC Registered Voters age 50 and older. June 2013. <http://www.aarp.org/nyc50plus>
2. *Aging in Place: A State Survey of Livability Policies and Practices*. A research report by the National Conference of State Legislatures and the AARP Public Policy Institute. December 2011. Available at <http://www.aarp.org/livable-communities/learn/research-trends/info-12-2012/aarp-aging-in-place-state-survey.html>
3. U.S. Census Bureau, American Community Survey, PUMS 2009-2011. Prepared by AARP Research.
4. MTA, NYC Transit Performance Dashboard. Available at [http://web.mta.info/persdashboard/agencies/nycibus/cp/166716\\_chartmth.htm](http://web.mta.info/persdashboard/agencies/nycibus/cp/166716_chartmth.htm)
5. NYC Department of Transportation. <http://www.nyc.gov/html/dot/html/pedestrians/safeseniors.shtml>
6. Centers for Disease Control, Morbidity and Mortality Weekly Report, Motor Vehicle Traffic-Related Pedestrian Deaths – United States, 2001-2010. April 19, 2013. Available at <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6215a1.htm#fig>
7. *Toward an Age-Friendly New York City: A Findings Report*. New York Academy of Medicine. Fall 2008. Available at [http://www.health.ny.gov/diseases/aids/conferences/docs/nyam\\_age\\_friendly\\_report.pdf](http://www.health.ny.gov/diseases/aids/conferences/docs/nyam_age_friendly_report.pdf)

**36%**  
50+ NYC  
Voters

**ARE NOT VERY CONFIDENT THEY CAN STAY IN THEIR CURRENT RESIDENCE WITHOUT NEEDING ANY MAJOR MODIFICATIONS AS THEY AGE<sup>1</sup>**

## VI. APPENDIX

- AARP 50+ NYC Voter Survey  
Method Statement
- Annotated Questionnaire of Results *(Note: The full survey annotation has been omitted from this printing but can be accessed online at [www.aarp.org/nyc50plus](http://www.aarp.org/nyc50plus).)*

# SURVEY METHODOLOGY

## SUMMARY

The AARP survey of New York City Voters obtained telephone interviews with a sample of 1,302 registered voters aged 50 and older who reside in New York City. The sample was drawn at random from a list of registered voters in New York City. The interviews were conducted in English and Spanish by Woelfel Research, Inc. May 28 through June 12, 2013. The results for the survey were weighted by age and gender. The margin of sampling error for the random sample of 1,302 is  $\pm 2.7\%$ .

There was an additional oversample of 305 Asian voters with a margin of error of  $\pm 5.6\%$ . Interviewing for the Asian oversample was conducted in English, Chinese, Korean, Hindi and Tagalog by Universal Survey June 17 through June 30, 2013. The Asian interviews were sampled from the same registered voter list and used the same survey instrument as the main sample, adapted into the appropriate languages. Data from the Asian oversample were weighted similarly by age and gender as well as ethnicity and county. Results reported for total New York City do not include data from the oversampled Asian respondents.

Details on the design and execution of the survey are discussed below.

## DESIGN AND DATA COLLECTION PROCEDURES

### **Sample Design**

The sample of registered voters was drawn from a list of 1.14 million registered voters complete with age, geography, and telephone number appended to the sample. The list was provided by Accudata, Inc. Respondents were screened to be 50 or older, to live in New York City and to be a registered voter in the state of New York. The sample sizes for the main sample by county were as follows:

- Bronx County            296
- Kings County            306
- New York County        304
- Queens County          309
- Richmond County        87

### **Questionnaire Development and Testing**

The questionnaire was developed by AARP staff. In order to improve the quality of the data, the questionnaire was pretested with a small number of respondents. The pretest interviews were monitored by WRI and AARP staff and conducted using experienced interviewers who could best judge the quality of the answers given and the degree to which respondents understood the questions.

# SURVEY METHODOLOGY

## Contact Procedures

Sample was released for interviewing in replicates, which are representative subsamples of the larger sample. Using replicates to control the release of sample ensures that complete call procedures are followed for the entire sample. It also ensures that the geographic distribution of numbers called is appropriate.

## WEIGHTING

The sample was weighted by county, age, race/ethnicity, and gender. The weights were applied sequentially. The order of application was county, age, race/ethnicity, and gender. The table below contains information about the weighting. The column labeled "Population" shows the actual population distributions for New York City registered voters aged 50 and older. The column labeled "Sample" shows the distribution of the sample. The column labeled "Weighted Sample" shows the distribution in the sample after the weights were applied. Since the Current Population Survey (U.S. Census Bureau) does not provide a weight target for "other" race, this category was given a weight of 1.

	Population*	Sample	Weighted Sample
Bronx	19%	23%	18%
Kings/Brooklyn	23%	24%	23%
New York/Manhattan	24%	23%	24%
Queens	26%	24%	26%
Richmond	8%	7%	9%
Age 50-59	36%	31%	35%
Age 60-74	47%	42%	48%
Age 75+	17%	27%	17%
White Non-Hispanic	51%	38%	48%
Black Non-Hispanic	27%	27%	25%
Hispanic	19%	24%	17%
Asian	3%	3%	3%
Other	(No target)	2%	2%
Missing		5%	5%
Male	43%	38%	43%
Female	57%	62%	57%

\* Source: U.S. Census Bureau, Current Population Survey, November 2010.

# SURVEY METHODOLOGY

## WEIGHTING, CONTINUED

ASIAN OVERSAMPLE	Population*	Sample	Weighted Sample
Bronx	5%	4%	3%
Kings/Brooklyn	24%	16%	19%
New York/Manhattan	16%	15%	14%
Queens	52%	59%	57%
Richmond	4%	7%	7%
Age 50-64	66%	46%	68%
Age 65+	34%	54%	32%
Chinese	54%	45%	54%
Filipino	8%	14%	8%
Indian	22%	17%	
Korean	10%		10%
Other (English speaking)	(No target)	7%	6%
Male	43%	33%	43%
Female	57%	66%	57%

State of the 50+ in NYC 2014

## RESPONSE RATE/COOPERATION RATE/REFUSAL RATE

The response rate for this study was measured using AAPOR's response rate 3 method. The cooperation rate was measured using AAPOR's cooperation rate 3 method. The refusal rate was measured using AAPOR's refusal rate 3 method.

	Response Rate	Cooperation Rate	Refusal Rate
Main sample	13%	78%	15%
Asian oversample	7%	40%	4%

Source: AAPOR Outcome Rate Calculator Version 2.1 May 2003



Real Possibilities

AARP New York  
780 Third Ave 33<sup>rd</sup> Floor  
New York, NY 10017  
Phone: (866) 227-7442  
Email: [nyaarp@aarp.org](mailto:nyaarp@aarp.org)  
Website: <http://www.aarp.org/ny>



## Contact Information:

PSS/WSF Grandparent  
Family Apartments  
PSS Kinship Caregivers Program

951 Prospect Avenue  
Bronx, NY 10459  
Tel: 718-620-1262 x1212  
Fax: 718-620-1267  
Toll Free Hot Line: 866-665-1713

Visit us at [www.pssusa.org](http://www.pssusa.org) to learn more about this innovative residence, our support programs and how you can be involved.

## Directions:

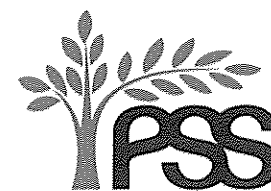
**Subway** — The building is located on the corner of Prospect Avenue and East 163rd Street two blocks north on Prospect Avenue from the Prospect Avenue Stop for the 2 and 5 subway lines.

**Bus** — BX 17 to 163rd Street and Prospect Avenue.

Gated parking is available in the rear – the entrance to the lot is on East 163rd Street.

The PSS/WSF Grandparent Family Apartments and Kinship Caregivers Program are funded with the support of many, including: NYOCFS, DYCD, SHFYA, and the U.S. Administration on Aging National Family Caregivers Support Program through the NYC Department for the Aging, as well as donor and community support.

PSS/WSF Grandparent Family Apartments  
& PSS Kinship Caregivers Program  
951 Prospect Avenue  
Bronx, NY 10459

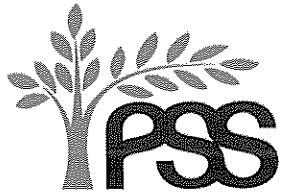


## PSS/WSF Grandparent Family Apartments & PSS Kinship Caregivers Program



*Serving the Needs of  
Grandparents Raising  
Grandchildren*





The PSS/WSF Grandparent Family Apartments (GFA) provide safe, affordable and supportive housing for grandparents raising grandchildren.

In the early 1990s, PSS was a pioneer in providing services to grandparents who unexpectedly found themselves caring for their grandchildren. In 2005, PSS partnered with the West Side Federation for Senior and Supportive Housing to open the first residence in the U.S. built specifically for grandparents raising grandchildren.

The GFA is the only residence of its kind in the entire state of New York. Visitors from across the U.S. and around the world regularly visit to learn from this nationally recognized and innovative model.

The fifty unit apartment building is home to over 50 grandparents and 100 grandchildren. The 40 two-bedroom and 10 three-bedroom modern apartments are designed to meet the needs of both older adults and children.

The building offers 24 hour front desk security, a library, a laundry room on each floor, senior and youth community rooms, and a green roof garden and relaxation area.



## SUPPORT SERVICES

The GFA serves as the hub for the **PSS Kinship Caregivers Program**. Professionally staffed by social workers and educators, this program offers a wide variety of services to both GFA residents and other families in New York City.

### Services for caregivers include:

- Support Groups
- Respite
- Counseling
- Intergenerational Programs
- Educational Workshops and Seminars
- Benefit and Entitlement Assistance

### For grandchildren, we provide:

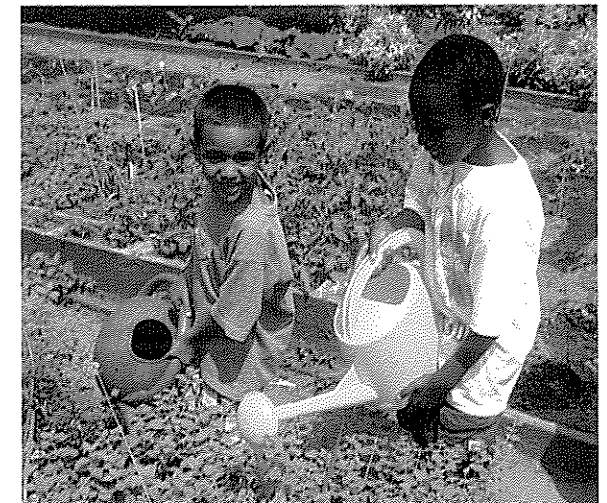
- After-School Program
- Recreational Activities
- Tutoring
- Summer Day Camp
- Job Readiness and Skill Building Training

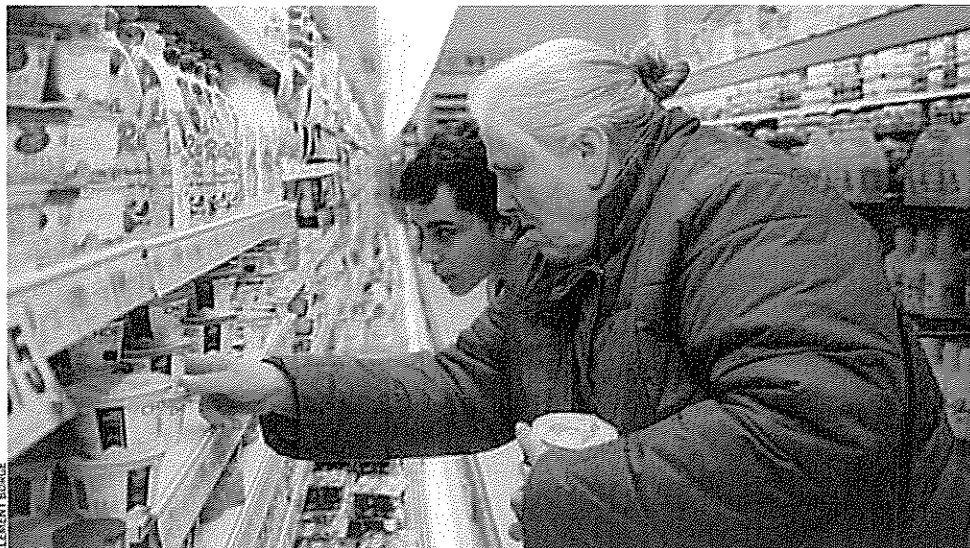
Across the United States, almost 7.8 million children are living in homes where grandparents or other relatives are the householders. (AARP GrandFacts)

According to the 2010 Census, in New York State close to 450,000 children under age 18 live in this type of household (10.2% of the children in the State).

Last year, our residence and on site support programs helped 120 children stay out of foster care, saving the State several hundred thousand dollars. 92% of these young people progressed to the next grade level in school.

To connect with the GFA and PSS' Kinship Caregivers Program, please visit our Website at [www.pssusa.org](http://www.pssusa.org) or call our toll free hotline: **866-665-1713**





**FAMILLE** Vinnie Fedele, 17 ans, aide sa grand-mère, Gail, 65 ans, dans les tâches du quotidien depuis que sa mère l'a abandonné (gauche). La famille Ces grand-mères y reçoivent de l'aide légale, financière et éducative pour apprendre, à un âge avancé, à gérer des enfants (droite).

## Quand grand-maman devient maman

**Reportage.** Aux Etats-Unis, de plus en plus de séniors se retrouvent à devoir élever leurs petits-enfants. Un immeuble à New York leur est consacré. Plongée dans un phénomène.

JULIE ZAUGG

**Vinnie est assis sur le lit de camp** qui trône au milieu du salon. Il pianote sur son smartphone d'un air absorbé. Avec ses traits fins, sa voix douce et sa petite taille, il paraît moins que ses 17 ans. «Dans deux ans, il va partir pour l'université, cela va être dur de le laisser s'en aller», soupire Gail Fedele, en le regardant tendrement. «M'man...», lâche Vinnie, sur ce ton mi-agacé, mi-indulgent que les adolescents réservent si souvent à leurs parents.

Gail Fedele n'est pas sa mère. Elle est sa grand-mère. Ses mèches grises, ses jambes lourdes, qu'elle trimballe à l'aide d'un déambulateur, et son visage ridé agrémenté d'un sourire taquin auquel il manque deux dents trahissent ses 65 ans. Elle élève Vinnie et sa sœur Cassandra, 18 ans, depuis leur enfance. «Leur mère me les a amenés un jour en Floride, où je vivais à l'époque, raconte-t-elle. Et n'est jamais venue les rechercher.»

Après deux ans de subsistance sur ses maigres économies, l'argent se met à manquer. La retraite de Gail Fedele, qui n'atteint que 648 dollars par mois, ne suffit plus à payer les factures. S'ensuit alors une transhumance de canapé en canapé, qui les amène à Chicago, puis en Caroline du Nord et finalement à New York en 2010. «Je suis arrivée en ville avec 300 dollars

en poche, relate cette native de Long Island. Ma fille avait promis de venir nous chercher à la gare, mais elle n'était pas là.»

Elle gagne alors un refuge pour sans-abri dans le Bronx. Ils y resteront trois ans, à vivre dans une minuscule pièce. «C'était très dur pour les enfants, se souvient-elle. Certains soirs, nous n'avions plus assez d'argent pour acheter à manger, alors nous sucions des glaçons pour faire passer la faim.» Un jour, un des gardes de sécurité du refuge lui parle d'un bâtiment réservé aux grand-mères qui élèvent leurs petits-enfants, à quelques blocs de là.

### UN MOUVEMENT QUI S'ACCENTUE

Le grand cube multicolore qui abrite ce havre tranche avec les HLM en brique rouge, si fréquentes dans ce coin du Bronx. Au rez, une pièce contient des ordinateurs et une table de billard. Sur le toit, un jardin urbain permet de prendre l'air. Les murs sont recouverts de panneaux qui expliquent comment cuisiner sainement avec un petit budget. «Cet immeuble, inauguré en 2005, est le premier du pays destiné spécifiquement aux grands-parents qui ont la charge de leurs petits-enfants», explique Rimas Jasin, directeur des Presbyterian Senior Services, l'ONG qui gère le bâtiment avec des fonds publics.

Tout a été réalisé pour servir au mieux ces deux générations. Pour les grand-mères,

«les salles de bain et les chambres à coucher ont été équipées de cordons d'urgence pour appeler à l'aide en cas de malaise. Et les corridors sont assez larges pour permettre le passage de chaises roulantes», explique le responsable. Une salle leur a été aussi réservée pour leur donner la possibilité de se retrouver une fois par semaine afin de partager leurs expériences et de régler les petits soucis des unes et des autres. Quant aux enfants, ils ont accès à des camps de vacances et à un programme de soutien scolaire.

Le bâtiment héberge une cinquantaine de familles, dont 56% sont afro-américaines et 43% hispaniques. Les loyers s'élèvent à 300 dollars en moyenne. «Nous sommes arrivés ici en mai 2013, se rappelle Gail Fedele, assise dans son trois-pièces au décor spartiate. Nous n'avons rien, alors les gérants de l'immeuble nous ont acheté des meubles, des vêtements et des manteaux d'hiver pour les petits.»

Comme Vinnie et sa sœur Cassandra, de plus en plus d'enfants sont élevés par leurs grands-parents. New York en comptait 450 000 en 2010, soit 10,2% des mineurs vivant dans cet Etat. «Ce phénomène a toujours existé, mais il a connu une immense croissance au cours de la dernière décennie», indique Laura Pittman, professeur de psychologie à l'Université de l'Illinois et spécialiste de cette ques-



vit aujourd'hui dans un bâtiment dédié spécialement aux grands-parents qui éduquent leurs petits-enfants, situé dans le Bronx (centre).

tion. Sur le plan national, 4,6 millions d'enfants vivaient avec leurs grands-parents en 2012, contre 3,8 millions en 2010.

Cette croissance du nombre de cas s'explique «le plus fréquemment par les problèmes de drogue et d'alcool de la mère ou son incarcération», détaille Linda Waite, une sociologue de l'Université de Chicago qui a étudié le phénomène. L'épidémie de méthamphétamine qui secoue les Etats-Unis y a contribué. Sont venues encore gonfler la statistique les mères adolescentes, les femmes soldats déployées ces dernières années en Afghanistan et en Irak, ainsi que la hausse des suicides. «Quant au père, il ne fait en général plus partie de leur vie», poursuit la sociologue.

Pour les grands-parents, la prise en charge de leurs petits-enfants représente un immense chambardement. «A une période de leur vie où ils pensaient pouvoir voyager et profiter de leurs loisirs, ils se retrouvent de nouveau dans un monde de biberons, de couches-culottes et de réunions scolaires», relève Sylvie Toledo, la fondatrice de l'organisation Grandparents As Parents, dans un livre consacré à la question. Pour eux, le problème le plus pressant est souvent d'ordre financier. «Certains vont devoir prendre une retraite anticipée, d'autres retourner travailler, d'autres encore puiser dans leurs avoirs de vieillesse», précise-t-elle. Plus de 70% des enfants élevés par leurs grands-parents vivent en dessous du seuil de pauvreté.

«Il y a en outre un fossé générationnel, relève Katherine Martinez, directrice adjointe de l'immeuble du Bronx. Les grands-parents ont grandi à une époque

où l'on menait les choses autrement, notamment sur le plan des relations amoureuses.» Issus d'un monde sans ordinateur, ils ont de la peine à comprendre – et à surveiller – ce que les jeunes font sur la Toile.

Il n'est pas non plus facile pour eux de se faire respecter par des adolescents qui jouent souvent la carte du «tu n'es pas ma mère», selon Rimas Jasin. «Et ces jeunes se posent tout un tas de questions: "Qui suis-je? Pourquoi m'a-t-on abandonné?" souligne Laura Pittman. Une incompréhension qui se manifeste par un comportement rebelle ou dépressif.» Du côté des grands-parents, c'est un mélange de colère et de culpabilité qui prévaut. «Ils sont fâchés contre leur propre enfant mais se demandent aussi ce qu'ils ont fait de faux dans son éducation», analyse Sylvie Toledo.

A l'évocation de ces observations, Gail Fedele a d'ailleurs le regard sombre, presque menaçant. «Je suis aussi en colère contre ma fille d'avoir délaissé ses enfants, très en colère, lâche-t-elle entre les dents. Elle ne s'est jamais vraiment intéressée à eux. Elle n'avait pas d'instinct maternel.» C'est Gail qui a trouvé le nom de Cassandra. L'adolescente vit très mal l'abandon par sa mère. «Elle a beaucoup de haine en elle, soupire sa grand-mère. Parfois, elle s'énervait contre moi, puis elle s'excuse. Elle ne sait pas comment exprimer ses sentiments.»

Tout n'est pas noir pour autant. «Lorsque les grands-parents prennent en charge l'éducation de leurs petits-enfants, cela leur évite d'être placés, indique Laura Pittman. Cela leur confère aussi un enracinement plus fort et une place dans l'histoire familiale.» De plus, les frères et sœurs ne sont pas séparés, comme c'est souvent le cas lors d'adoptions.

Gail Fedele ne regrette pas une seconde d'avoir pris ses petits-enfants sous son aile. «Ce sont de bons gamins. Ils n'ont jamais touché à la drogue ou traîné dans la rue. Leur enfance leur a appris l'importance de ne pas déraper.» Vinnie, en particulier, semble promis à un bel avenir. Enrôlé dans une multitude de programmes extrascolaires, il fréquente un lycée pour élèves doués spécialisé dans les mathématiques. «Je veux étudier les neurosciences», glisse-t-il avec un grand sourire.

Fin août, le bâtiment des grands-parents accueille son événement de mise en réseau annuel. Une table a été dressée avec un buffet de viennes en cage et de rouleaux de printemps. Un grand bol rouge attend les cartes de visite. Cette manifestation a pour but d'aider les adolescents de l'immeuble à rencontrer des professionnels: travailleurs sociaux, policiers ou infirmières. Vinnie s'est mis sur son trente et un. Il porte une chemise rayée et un pantalon bleu marine. Il s'approche d'un pas assuré d'un homme en complet. «Bonjour Monsieur, je m'appelle Vinnie...» ■

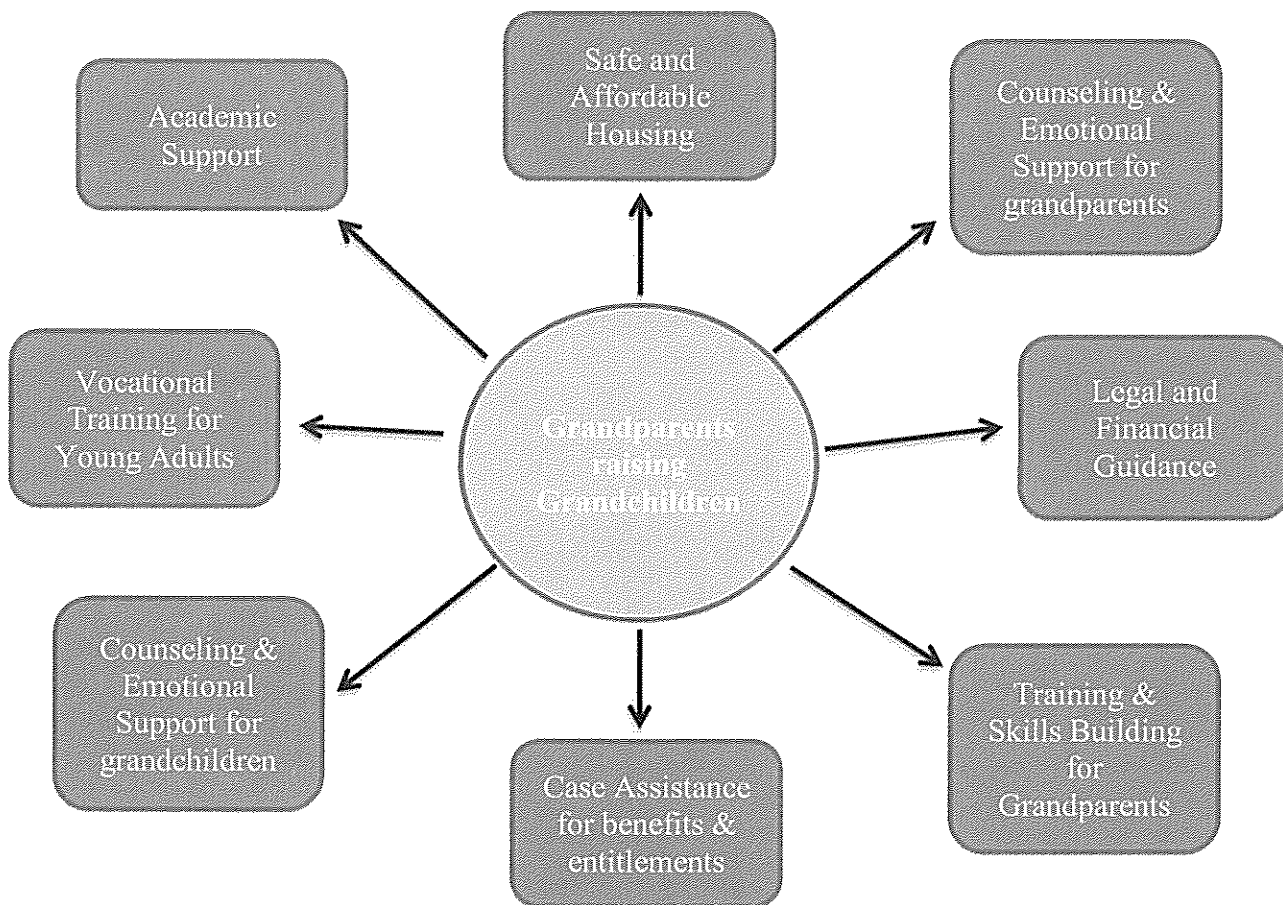
« Je suis aussi en colère contre ma fille d'avoir abandonné ses enfants, très en colère. »

GAIL FEDELE



The PSS/WSF Grandparent Family Apartments will be celebrating its 10<sup>th</sup> Anniversary in 2015. Over the years, PSS has developed an expertise and best practices in effectively serving kinship families.

The needs of kinship families are multi-dimensional. Needs and issues change and evolve as families change and evolve over time.



**Recommendations:**

1. Funding for kinship services needs to be dramatically increased.
2. Funding support for kinship services should be more multi-dimensional.
3. Grant opportunities should focus more on comprehensive and holistic approaches and that build on the best practices that agencies currently provide.

Coming  
of Age  
NYC

Family  
& Kinship  
Caregiver  
Services

Youth  
Caregivers  
Initiative

PSS  
Alberta L. Alston  
Apartments

Grandparent  
Family  
Apartments

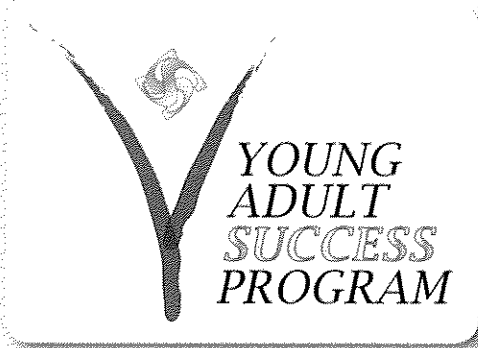
Young Adult  
Success Program  
(YASP)

PSS  
Senior  
Centers

PSS  
Volunteer  
Services



2014  
ANNUAL REPORT



**YASP -- The newest PSS initiative aims to have a lasting impact on young adults being raised by grandparents.** Just a small amount of time every week or two can change someone's life!

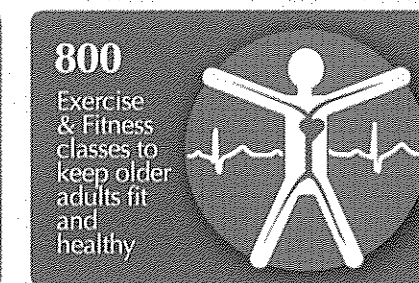
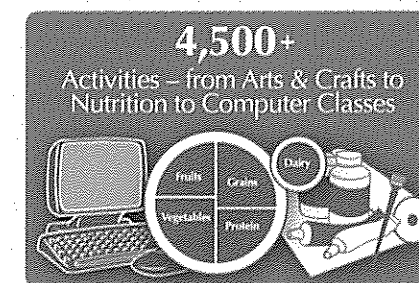
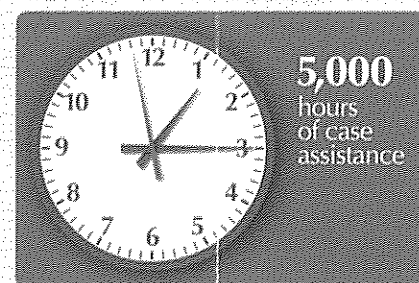
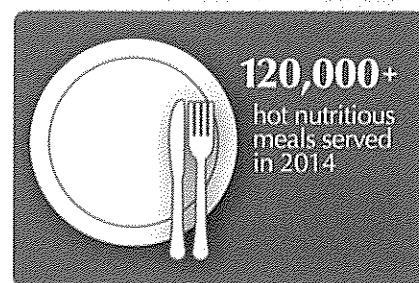
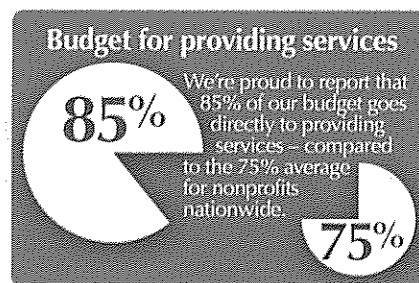
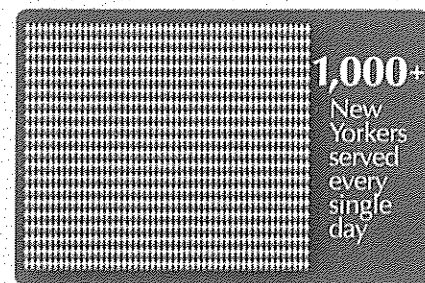
YASP recruits working professionals to serve as "Success Coaches" for neighborhood high school students and young adults living in the PSS/WSF Grandparent Family Apartments who need guidance on careers and colleges. Coaching is done primarily through telephone, email, and texts. PSS recruits, trains and supports the

volunteer coaches. To learn more about this exciting new initiative, please contact Rosaly Ocasio at 718-620-1262 ext 1211 or email [rocasio@pssusa.org](mailto:rocasio@pssusa.org).



**PSS Family and Kinship Caregiver Services support families throughout the Bronx struggling with their caregiver needs, whether for the elderly or for youth they are raising.**

- A working caregiver, overwhelmed from caring for her elderly mom suffering with dementia, receives assistance in applying for Medicaid and homecare services and is provided with needed respite, homecare services, counseling, and caregiver support groups.
- A grandmother raising her two school aged grandchildren in a Bronx homeless shelter reaches out to the PSS Kinship Caregivers Support Program for help. A PSS Caseworker, successfully secures for the family both housing and support at the PSS/WSF Grandparent Family Apartments.
- An elderly caregiver for his wife with Parkinson's disease discovers they are not eligible for Medicaid nor can they afford private home care. He reaches out to the PSS Caregivers Support Program and receives the help needed - including counseling and respite.



PSS has always relied on wonderful volunteers. However, thanks to a generous grant from the Florence V. Burden Foundation, PSS had the opportunity to create a brand new position and hired Kimberly Reid as its first Volunteer Services Manager. In addition to developing a comprehensive volunteer program for all of PSS's centers and

departments, the volunteer program fielded nearly 200 inquiries and placed over 50 new volunteers this past year. PSS now has over 100 active volunteers and continues to grow rapidly. Volunteer opportunities range from helping at senior centers to mentoring young adults, and they can be one-time activities like assisting with holiday parties to long-term assignments such as helping with administrative tasks.

For more information please contact Kimberly at 718-585-1640 or email [kreid@pssusa.org](mailto:kreid@pssusa.org).



Coming of Age NYC's programs help New Yorkers 50+ explore opportunities, engage with their community, connect with others, and lead a more fulfilling life. Coming of Age NYC collaborates with nonprofits, health care agencies, government organizations, faith-based organizations, and businesses to help them further their mission by recruiting and maintaining volunteer New Yorkers age 50+. Coming of Age NYC programs include the **Explore Your Future** Workshop Series, **Capturing the Energy** training for nonprofit staff, and Networking Socials and Special Events for active adults age 50 and older.

For more information, please visit [www.comingofagenyc.org](http://www.comingofagenyc.org) or call 212-874-6633 x 21.

# Thank You to our Major Contributors

## Major Supporters (\$1000 and above)

AARP New York  
David & Minnie Berk Foundation  
CenterLight Healthcare  
EmblemHealth Services  
Fifth Avenue Presbyterian Church Women's Association  
The First Presbyterian Church in the City of New York  
Presbytery of New York City  
The Riverside Church  
Joan L. & Reade Ryan, Jr.  
West Side Federation for Senior & Supportive Housing

The Barker Welfare Foundation  
Florence V. Burden Foundation  
Emilie Roy Corey  
Fifth Ave Presbyterian Church  
Generations United  
HANAC  
Ann M. Reed  
Rutgers Presbyterian Church  
Elizabeth & Jerome Schneewind

## Institutional and Government Funders

Bronx Borough President Ruben Diaz Jr.  
NYC Council Member Inez Dickens  
NYC Council Member Ritchie Torres  
NYC Department for the Aging  
NYC Service  
Supportive Housing for Families and Young Adults

NYC Council Member Maria del Carmen Arroyo  
NYC Council Member Vanessa Gibson  
NYC Council Member James Vacca  
NYC Department of Youth and Community Development  
New York State Office for the Aging

---

**Special Thanks to Rutgers Presbyterian Church for its generous support and donating valuable office space for PSS's administrative offices.**

---

### Board of Directors

Martha M. Ferry, President  
Tina Stinson-DaCruz, Vice President  
Alice Hudson, Secretary  
Josephine Cameron  
John Downing  
Sheila D. Johnson  
Elgie Powell  
Elizabeth Schneewind  
Lisa Sisenwein

Rimas J. Jasin, Executive Director  
Katherine Martinez, Deputy Director  
Barbara Hernandez, Finance Manager  
Susan Friedman, Communications Coord.

### How You Can Make a Difference

- Donate – visit our website to make a secure online contribution
- Volunteer your time to one of our worthwhile programs
- Stay informed – visit our website and sign up for our E-Newsletter

**VISIT US AT [WWW.PSSUSA.ORG](http://WWW.PSSUSA.ORG)**

Marie Joseph Modeste  
**Alberta Alston House**  
52-09 99th Street  
Corona, NY 11368  
718-271-0245

Michele Chapple  
**Davidson Senior Center**  
950 Union Avenue  
Bronx, NY 10459  
718-328-2810

Marilyn Green  
**Highbridge Senior Center**  
1181 Nelson Avenue – Floor 2  
Bronx, NY 10452  
718-588-3004

Kimberley Brace  
**Kinship Program**  
951 Prospect Avenue  
Bronx, NY 10459  
718-620-1262 x1213

Julissa Sosa  
**Caregivers Support Program**  
325 East 156th Street  
Bronx, NY 10451  
718-585-1640

Patricia Attis  
**City Island Senior Center**  
116 City Island Avenue  
City Island, NY 10464  
718-885-0727

Jessica Vazquez  
**Harlem Pelham Fritz Senior Center**  
18 Mount Morris Park West  
New York, NY 10027  
212-222-3132

Anya Metlitsky  
**Andrew Jackson Senior Center**  
325 East 156th Street  
Bronx, NY 10451  
718-585-1640

Liz Robinson  
**Parkside Senior Center**  
644 Adee Avenue  
Bronx, NY 10467  
718-881-7780

Kimberly Reid  
**Volunteer Services Manager**  
325 East 156th Street  
Bronx, NY 10451  
718-585-1640

New York City Council Committee on Aging and Committee on Immigration

Hearing on Oversight: Providing Support to New York City's Caregivers

Margaret Chin, Chair, Committee on Aging

December 9, 2014

Testimony presented by

Matt Kudish

Senior Vice President

Director of Caregiver Services

Alzheimer's Association, New York City Chapter



Thank you for the opportunity to discuss the issues of Caregiving for New York City's Senior Services. I am Matt Kudish, Senior Vice President of Caregiver Services at the Alzheimer's Association, New York City Chapter. Founded in 1978, the Chapter is one of seven statewide and 83 nationally that deliver services and provide care and support, free of charge. The New York City Chapter serves an estimated 500,000 New Yorkers—those with Alzheimer's and related disorders and their caregivers.

Alzheimer's is a progressive and fatal brain disease, mostly affecting the elderly, which threatens to overwhelm the health care system, if we do not find a way of preventing, or hopefully curing it one day. Approximately 5 million people in the United States are living with Alzheimer's disease – 5% reside in New York City. That number is expected to grow to as many as 16 million by mid-century. Every 67 seconds a person in the United States is diagnosed with Alzheimer's disease and we expect by 2030 there will be 7 million people age 65 and older living with Alzheimer's. The financial ramifications of the disease are daunting and currently cost America \$214 billion annually.

Today, an estimated 250,000 people in the New York City area, diagnosed with dementia or Alzheimer's disease, are living with losses that are unimaginable to those of us who do not suffer from this illness. This debilitating disease not only robs persons with dementia (PWD) of their memory but also causes problems with thinking and behavior severe enough to adversely impact nearly every aspect of their daily lives. The PWD is no longer able to work, enjoy lifelong hobbies or social life. The lives of their family members are profoundly affected as well. They become increasingly isolated as their caregiving responsibilities escalate. Alzheimer's and other dementias are one of the leading causes of dependency and disability in older adults.

The Alzheimer's Association, NYC Chapter is on the front lines every day providing a wide variety of educational and support programs including over 110 monthly support groups, the MedicAlert® + Safe Return® Program, a 24-hour Helpline and Care Consultation services with professional counselors all designed to assist caregivers, family members and persons with dementia develop methods for successfully coping with this progressive and terminal illness. We also train home care workers and others to better care for persons with dementia. A major focus

for the Chapter is outreach to the Latino, Chinese, African-American, Russian, LGBT, and Orthodox Jewish communities and other underserved and immigrant populations.

Today's hearing is focused on providing support to New York City's caregivers.

New York City's population is aging rapidly. As of 2010 there are an estimated 1 million New Yorkers over the age of 65, with that number set to rise in the coming years. With this aging population, New York City must pay specific attention to the social and health concerns of seniors, which include Alzheimer's disease and related dementias, associated care requirements, and caregiver support.

Caring for a relative with AD is an exhausting and demanding task, one that is often done out of a deep sense of love, duty and filial obligation, but in many cases the relationships are fractured, and there is deep resentment and frustration. Usually it is a mix of emotions, colored by bone-tiring fatigue, and even the best intentioned caregiver quickly is drained of his or her emotional, spiritual as well as financial resources. The physical effects of caring for a person with dementia are well documented.

Our national report on Alzheimer's disease and caregiving, *2014 Alzheimer's Disease Facts and Figures*, shows that in 2013, 15.5 million caregivers provided an estimated 17.7 billion hours of unpaid care to PWDs nationwide. This care is valued at \$220.2 billion. The extensive, specialized care requirements essential to the PWD can take a serious emotional and physical toll on the caregiver. Caregivers are known to neglect their own health and needs as a result of their responsibilities. This burdens caregivers with physical illness, depression, fatigue, and increased medical expenses of their own. In 2013, Alzheimer's caregivers had an additional \$9.3 billion in healthcare costs.<sup>1</sup>

At the NYC Chapter we have worked with many thousands of caregivers over the years and there are countless stories to exemplify the impact of caregiving on one's well-being. A man in his 80s caring for his wife with Alzheimer's disease, who is awoken in the middle of the night, every night, by his frightened wife who is unsure of who he is and what he is doing in her bed. When nothing he says calms her down, he is forced to leave the apartment and wait in the hall

---

<sup>1</sup> Alzheimer's Association, *2014 Alzheimer's Disease Facts and Figures*, Alzheimer's & Dementia, Volume 10, Issue 2, page 30.

for ten to fifteen minutes until he can re-enter, greeting his wife as if he has just returned home from work in order to distract her and get them both back to sleep. A woman with Alzheimer's whose six children take turns using their vacation time to rotate their caregiving responsibilities in order to ensure Mom is never alone and gets the care she deserves, never able to use their vacation time for themselves. A man caring for his wife with dementia who ensures she makes it to her regular doctor appointments. He is not a patient of this doctor, but the doctor notices he is limping and asks if she can look at his leg only to find a wound so seriously infected that he requires immediate hospitalization. When asked why he hadn't sought medical assistance, he shares that he can deal with his health issues later but that his wife needs him now.

Presently, New York City is unprepared to meet the needs of the estimated 250,000 persons living with Alzheimer's disease or other forms of dementia and their caregivers. *Crisis for Caregivers: Alzheimer's Disease in New York City*, a 2013 survey and report published by the Alzheimer's Association, New York City Chapter in partnership with the office of former Manhattan Borough President, Scott Stringer shows the significant impact of Alzheimer's disease and related dementias on New York City and the inadequate support or awareness of support provided to caregivers. Our findings revealed the following:

- Caregivers spend significant amount of time providing unpaid care to their family member or friend each week, with 40 percent spending as many or more than 40 hours per week providing unpaid care.
- A majority of respondents, two thirds, missed at least one day of work due to caregiving responsibilities. Seventeen percent missed 21 days or more of work.
- Survey respondents are deeply dissatisfied with the level of services and support provided to persons with Alzheimer's disease in New York City and their caregivers. More than 95 percent of respondents believe there needs to be a citywide plan to address Alzheimer's disease and related dementias in New York City—both for persons with the disease and their caregivers.

Persons with dementia, their families and caregivers face unique challenges when navigating New York City services. It is critical to look at the experience of caring for a family member with dementia through the lens of the caregiver, who is often emotionally and physically stressed and cannot spare the time to search for assistance.

To increase and improve access to New York City's senior and caregiver services the Alzheimer's Association recommends the following action items:

- The New York City Council, Department of Health and Mental Hygiene and Department for the Aging should consider making information on aging-related health conditions, such as Alzheimer's disease and dementia, more accessible through web and print media. For example, the NYC DOHMH site should list Alzheimer's disease and/or dementia clearly on its "Health Topics A-Z" page.
- New York City should also produce a public awareness campaign to educate residents on the signs of Alzheimer's disease and dementia and where to turn for help, including available services for caregivers, which are underutilized.
- New York City should promote the Department for the Aging's Alzheimer's and Caregiver Resource Center and the Alzheimer's Association 24-hour Helpline.
- Fund Caregiver Support Services \$3 Million– Consistent with the recommendation from CSCS. The only funding available for caregiver support services is through the federal Older Americans Act. NYC needs to allocate funding because providing supportive services for the caregiver is key to maintaining his or her own wellbeing and that of the person with dementia.. This includes respite care, home care or a temporary placement, to allow the caregiver to attend to daily chores, get their hair cut, attend a support groups, education program or simply have some down time. Listening to caregivers and what they identify as their needs is key. Connecting the caregiver to other services is also important. Funding should be baselined.

The Alzheimer's Association, New York City Chapter stands ready to provide expert guidance and assistance in considering these matters.

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12/9/14

(PLEASE PRINT)

Name: Alicia Fry, LMSW

Address: \_\_\_\_\_

I represent: Services Now for Adult Persons

Address: (SNAP), Inc.

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12-9-14

(PLEASE PRINT)

Name: Barbara Graves-Poller

Address: 299 B'way 4th fl. NYC 10007

I represent: MFY Legal Services, Inc.

Address: 299 B'way 4th fl 10007

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Erin Brennan

Address: \_\_\_\_\_

I represent: Selfhelp Community Services

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

[ ]

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12/9/14

(PLEASE PRINT)

Name: Shyvonne Noboa

Address: 4231 39th St. Bay side

I represent: Bay side Community Svcs.

Address: Same.

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

[ ]

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: JAMES ARNOLD

Address: 411 E 90th St 2E

I represent: AARP NY State

Address: 380 7th Av NYC

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

[ ]

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Kim Hernandez

Address: Assistant Commissioner, Active Aging

I represent: DFIA

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12-9-14

(PLEASE PRINT)

Name: Robin Fenley, PhD, LCSW  
Address: Deputy Assistant Commissioner, Long-Term  
I represent: Care  
Address: DFTA

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Giovanna Montalvo Baer  
Address: Director, Grandparent Resource Center  
I represent: DFTA  
Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Dr Robin Fenley  
Address: \_\_\_\_\_  
I represent: Nyc Dept for the Aging  
Address: 2 Lafayette St

Please complete this card and return to the Sergeant-at-Arms

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12/9/14

Name: Bob Row (PLEASE PRINT) GINS JARVIS

Address: 44 BOND ST 23 ST

I represent: NYFCU, South East

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12/9/14

Name: Bobbie SACKMAN (PLEASE PRINT)

Address: 49 W 45 ST

I represent: Council of Jr Centers & Services

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: 12/9/14

Name: Molly Krakowski (PLEASE PRINT)

Address: \_\_\_\_\_

I represent: JASA

Address: \_\_\_\_\_



**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: KEVIN Queen

Address: 11 Park Place #1416 NYC 10007

I represent: NY Foundation for Senior Citizens

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: RIMA S JASIN, EXEC. DIRECTOR

Address: P55 GRANDPARENT FAMILY APARTMENTS

I represent: \_\_\_\_\_

Address: \_\_\_\_\_

**THE COUNCIL  
THE CITY OF NEW YORK**

Appearance Card

I intend to appear and speak on Int. No. \_\_\_\_\_ Res. No. \_\_\_\_\_

in favor  in opposition

Date: \_\_\_\_\_

(PLEASE PRINT)

Name: Judy W. H. G

Address: \_\_\_\_\_

I represent: Heights and Hills

Address: 57 Willoughby St Brooklyn

Please complete this card and return to the Sergeant-at-Arms