Department for
the Aging

TESTIMONY

Presented by

Donna M. Corrado, PhD
Commissioner

on

Int. 1081: Comprehensive Plan to Address the Needs of Informal Caregivers

before the

New York City Council
Committee on Aging & Committee on Civil Service and Labor

on

Monday, April 11, 2016
1:00 P.M.

at

Council Chambers, City Hall
New York, NY 10007

Good afternoon, Chairpersons Chin, Miller and members of the Aging and Civil Service and Labor Committees. I am Donna Corrado, Commissioner of the New York City Department for the Aging (DFTA). I am joined today by Caryn Resnick, Deputy Commissioner for External Affairs, and Robin Fenley, Assistant Commissioner for the Bureau of HealthCare Connections and Director of the Alzheimer's & Caregiver Resource Center. Thank you for the opportunity to discuss Int. 1081, in relation to a comprehensive plan to address the needs of informal caregivers.

Millions of people throughout the U.S. are informal caregivers. More than 44 million individuals provide care for family members who are chronically ill, disabled or aged across the country.[1] 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.[2] Approximately 1.3 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.[3] The average time spent in providing care is more than 24 hours per week, which is, essentially, a second job for many caregivers.[4] Nearly 1 in 4 caregivers spends 41 hours or more per week providing care.[5] The economic value of these informal caregivers, should these services be provided by paid caregivers, is an estimated $470 billion per year.[6]

In addition, 2.7 million grandparents serve as the primary caregiver for their grandchildren.[7] 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.[8] One-fifth, or 22 percent, of grandparent caregivers are living below the federal poverty line, while 10 percent among the

---

[1] Family Caregiver Alliance – National Center on Caregiving. National Policy Statement.
[2] Family Caregiver Alliance – National Center on Caregiving. Caregiving Across the States: 50 State Profiles – 2014 Update. State Profile: New York.
[3] AARP, LiveOn NY and New York State Caregiving and Respite Coalition. Report: Caregivers in Crisis – Why New York Must Act, November 2013.
[4] National Alliance for Caregiving and AARP. Caregiving in the U.S., 2015.
[5] Id.
[6] AARP Public Policy Institute. Valuing the Invaluable: 2015 Update.
[7] Ellis and Simmons. Coresident Grandparents and Their Grandchildren: 2012. Population Characteristics, October 2014.
[8] Livingston. Pew Research Center. At Grandmother's House We Stay, September 4, 2013.

general population of individuals ages 50 and older are below the federal poverty line.[9] In New York City, about 66,000 grandparents are raising grandchildren under 18 years old.[10]

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

---

[9] Id.
[10] 2010 U.S. Census.

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 and benefits; 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 with bathing, dressing, eating, ambulating, or using the toilet, or be cognitively impaired, requiring verbal cueing, or substantial supervision.

Under supplemental services, which are designed to provide non-traditional assistance, the requirement for two ADLs and cognitive impairment 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 & 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 '16, DFTA's ten caregiver programs have served approximately 9,000 individuals throughout the City since July of last year, providing information about caregiving, discussing the associated stressors and offering pertinent resources, such as respite and supplemental services. Also available for caregivers through these programs is supportive counseling, support groups and training.

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. The remaining three programs assist caregivers citywide: one program serves Chinese, Japanese and Korean caregivers; another program serves the blind and visually impaired; and the 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, while also providing information to attendees. Programs also take advantage of local media outlets, such as public television and community newspapers, to discuss caregiving and available services through the Caregiver program.

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. This is being seen with the grandparent who has begun to show signs of cognitive impairment, whereby the grandchild now cares for their grandparent. 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 for as long as possible.

Assistance is also available through the social work staff of DFTA's Alzheimer's & Caregiver Resource Center, who have provided information and referral to more than 3,400 individuals since last July. Resources discussed with callers include alternative residential options for their care receivers who can no longer safely reside at home, discussion on accessing the needed long term supports, and linkages to appropriate community services. Consultation is provided to other professionals who are seeking services for their clients and are not familiar with aging resources.

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 services received through the Caregiver Support Program. 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 LiveOn NY. DFTA participated in the early development of this Coalition, as well as the Partnership for Family Caregiving Corps, a corporate focused coalition spearheaded by 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.

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. In calendar year 2015, there were 737 grandparent caregivers served. Through the GRC, more than 3,240 service units were provided, which include case assistance, counseling, information, training, and support group participation.

In order to serve some of the neediest kinship caregiver families, the GRC program expanded in FY '15 under the Mayor's New York City Housing Authority (NYCHA) Anti-Violence Program. The GRC received $472,000 beginning 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 have received grandparenting education, trainings and peer support on raising children.

INT. 1081: COMPREHENSIVE PLAN TO ADDRESS THE NEEDS OF INFORMAL CAREGIVERS

The Administration shares the concerns prompting the introduction of Int. 1081, as supporting the needs of informal caregivers is of paramount importance. Family caregiving is a well-researched area. Developing and conducting a survey of informal caregivers, service providers and service recipients within the City to assess existing informal caregiver services, and to identify the needs of informal caregivers will require technical proficiency and resources outside of DFTA's capacity. To conduct such research, it is critical to determine achievable objectives and apply valid research methodology. Academic and research institutions have the depth of knowledge and technical expertise required to comprehensively conduct the survey as proposed.

Furthermore, the legislation includes "adults providing unpaid care to individuals with disabilities between the ages of 18 and 59" in the definition of informal caregiver. DFTA, however, does not provide services for caregivers for individuals with disabilities within this age demographic. DFTA primarily serves informal caregivers who assist older adults who are physically and/or cognitively impaired, as well as older adult caregivers who are raising grandchildren or other younger kin.

CONCLUSION

Thank you again for this opportunity to provide testimony on Int. 1081. I am pleased to answer any questions you may have.

NATIONAL DOMESTIC
WORKERS ALLIANCE

Testimony of Irene Jor, New York Organizer
National Domestic Workers Alliance

In Support of Int. No. 1084 and 1081

Presented Before the New York City Council Committee on Aging and Committee on Civil Service and Labor

April 11, 2016 at 1:00 pm

Good afternoon, my name is Irene Jor and I work as the New York Organizer at the National Domestic Workers Alliance, and also act as the coordinator for the New York Domestic Workers Coalition. I am testifying today regarding bills 1084 and 1081. Both pieces of legislation are critical to establishing a more caring economy here in New York City.

Our coalition and members are especially excited about the prospect of a Division of Paid Care. In 2015 we celebrated the 5th anniversary of the New York State Domestic Worker Bill of Rights, and also began to work through shared lessons around the challenge of implementation and enforcement. We know first hand that winning domestic workers inclusion in labor protections is just a first step, and it takes strong worker organizing and systems for collaboration between enforcement agencies and community organizations to truly deliver change in this industry.

As a community we have formulated the following recommendations for the Division of Paid Care:

Recommendations for Int. No. 1084

- ***Identify more concrete ways of reaching out to and making interventions pertaining to childcare workers are identified and defined in the proposed bill.***

- ***Include referral agencies as one of the entities that should be regulated in conjunction with home care services agencies.*** While they are not "employers" like the home care agencies, such referral agencies connect many childcare workers with work in private residences.

There is some level of regulation already under New York City law. The Department of Consumer Affairs should be enforcing a city law that requires employment agencies to have domestic employers sign a statement of their responsibilities, and to provide workers with a written statement of their rights. If violated the agency can be fined up to $1,000 or face 1-year of imprisonment. It is not clear if this has been enforced effectively. As such, this bill should reference those regulations and make sure it comports with existing requirements to ensure that "referral agencies" are not off the hook in any way. It would be beneficial to include this in both the industry research and also systemic legal violations investigations conducted by the division.

Many referral agencies used by domestic workers are also small immigrant businesses and it would be good to work with Small Business Services to promote a high-road agency program.

- ***Explicitly include collaboration with worker centers and community-based organizations as a key principle.*** Domestic worker and employer outreach, education, and compliance with labor laws has been deeply explored and undertaken by a number of worker centers and community based organizations in New York. It would be more efficient, effective, and likely to scale such efforts by designing a partnership with these organizations and contracting them to do this some of this work to reach specialized populations with whom they have experience working with.
    - San Francisco's Office of Labor Standards and Enforcement has employed a model of working with local progressive worker organizations to enforce city level labor protections, minimum wage, paid sick days, and also the wage theft ordinance since 2008. The same organizations that fought for many of these protections were then contracted by the city to support the laws' implementation and enforcement. This collaborative model of enforcement has incredible potential.
- ***Connect paid care workers to trainings that are outside the limited scope outside those that are 'state approved'.*** In the bill 'state approved' is also focused on state regulated direct care work, much of the care workforce operates in the informal sector, and are in roles that are not regulated by the state, but these are workers that nonetheless would benefit from accessing our network's programs.

  Referrals should be made to training programs that are hosted by worker centers and community organizations. Many worker centers and community-based organizations also provide professional development support that is focused on supporting the career growth of domestic workers and care workers in the informal sector. Worker centers and community-based organizations have created nuanced multilingual and holistic programs that are not just focused on adding depth to care skill sets but that also provide job readiness training. While most worker center and community-based organization training programs are not 'state approved,' or focused on state regulated positions, they play a pivotal role in supporting the growing informal care workforce, acting as a means of skill development, career progression enablers, and cornerstones of providing higher quality care. They also serve workers, mainly undocumented, immigrant women of color, that face barriers in accessing traditional supports, and work to prevent further labor market stratification.

- ***Account for other existing intake systems and legal assistance offered to paid care workers in designing the Division's overall intake and referral infrastructure.***

- ***Facilitate a regular or as needed meeting between groups and enforcement entities to track the progress of cases.***

- ***Expand the research conducted to gather data goes beyond demographics in the industry and also identify facts that support the implementation & enforcement of labor protections for the paid care workforce***, including but not limited to:

    - Working conditions & market standards
    - Employer compliance with current labor laws, and the barriers and/or resistance that lead to employer non-compliance.
    - The practices of entities offering referral or placement assistance to domestic employers overall, not limited to residential home care agencies.

Develop a public education campaign on safe & healthy home-based workplaces & house cleaning, educating both employers and workers about health and safety issues in the domestic home environment. While housecleaning does not fall under the category of paid care, we know that there is level of fluidity and continuity between house cleaning and care work. Paid care workers are often also providing house cleaning in their role. It is important to ensure that the homes they are working, and the work they are expected to engage in is as safe & healthy as possible.

Though this may fall outside of the Division of Paid Care, we encourage the Office of Labor Standards to consider providing some matching level of attention in its programs and policies to supporting housecleaners.

- ***Create an advisory board of paid care workers, employers, care consumers, and advocates to review the Division's work, provide feedback and strategic direction, and also formulate fair standards that private employment relationships can use as guidelines on an annual basis.***

With regards to bill 1081, we know this legislation not only impacts the families that many domestic workers have employment relationships with, but also their own families. Many domestic workers also carry incredible family and community caregiver responsibilities. Though they were not able to make it today, our members Marlene Champion and Barbara Bruce wanted to share their personal stories and have submitted written testimony for this hearing. I hope you will take the time to also learn about how both these bills may impact their lives.

NATIONAL DOMESTIC
WORKERS ALLIANCE

Testimony of Allison Julien, New York Organizer
National Domestic Workers Alliance

In Support of Int. No. 1084

Presented Before the New York City Council Committee on Aging and Committee on Civil Service and Labor

April 11, 2016 at 1:00 pm

Good afternoon ladies and gentlemen,

My name is Allison Julien and I am a New York organizer with the National Domestic Workers Alliance. I have been a nanny in the New York area for over 20 years and I have been organizing domestic workers across the city for more than 13 years. In those 13 years I was part of the organizing that led to the passage of the country's first Domestic Worker Bill of Rights here in New York. The passage of the New York State Domestic Worker Bill of Rights in 2010 was a historic victory for hundreds of thousands of domestic workers.

I am testifying today in support of bill no. 1084 to establish a Division of Paid Care in the city's Office of Labor Standards because it is important for domestic workers to have a place to go to learn about their rights and get the support needed to enforce them.

Having been a nanny for over two decades, I have seen first-hand the ways legal protections and visible government agency support provide an affirmation to domestic workers that their profession is REAL WORK and is protected by laws. Implementation and enforcement is still a challenge. The enforcement of the bill and other protections that domestic workers have, including NYC's paid sick leave, depends on the workers' awareness of their rights and employers' awareness of their obligations. Information and resources on rights and responsibilities can be hard to come by. Public education has been limited, and at this stage falls largely on community-based organizations like those in the New York Domestic Workers Coalition, which have limited resources and are unable to sustain and scale their efforts alone. The Division of Paid Care could be a way for us to get creative about continuous education and outreach efforts AND collaboration between government and community partners. In addition to education, the Division can play a role in lifting up the visibility and value of domestic work in New York City.

As a former nanny, I would also like to see the bill amended to include employment referral agencies, in addition to home care services agencies, in both the industry research and also systemic legal violation investigations conducted by the Division. From the many years of hearing from my peers in domestic work about the types of jobs they received through agencies, I know they are often lower paying, longer hours, and involve extensive job responsibilities that seemed to just keep piling on. Workers often times do the job of a nanny and housekeeper and working 12 to 14 hours days without overtime pay is not uncommon. I do believe agencies have had a role to play in allowing these standards to be so low. Employers know these agencies can deliver vulnerable workers who are willing to accept these conditions, and often agencies do not share an accurate job description or information with workers about their rights. Workers are also paying ridiculous fees, sometimes one to two weeks of their salary, to use many of these agencies. These agencies need to be investigated; we need to pressure them to raise their standards when they do not uphold the law. Consequences and penalties need to be in place for such violations from agencies.

I hope the Division will also recognize the important role that community-based organizations have to play in truly transforming the landscape of the domestic work industry and support workers in connecting with them. They offer workers the opportunity to find a community in which they can belong, and secure longer-term support needed to navigate this industry. I know this firsthand because my journey started exactly this way 13 years ago.

NATIONAL DOMESTIC
WORKERS ALLIANCE

Testimony of Maggie Marron, Law & Policy Fellow
National Domestic Workers Alliance

In Support of Int. No. 1084

Presented Before the New York City Council Committee on Aging and Committee on Civil Service and Labor

April 11, 2016 at 1:00 pm

Good afternoon. My name is Maggie Marron and I am the Law & Policy Fellow at National Domestic Workers Alliance. You have heard from some of my colleagues about the great potential the Division of Paid Care represents for homecare workers and nannies more broadly, so I will simply address the provision of Int. No. 1084 requiring the Division of Paid Care to develop an intake system for paid care workers to submit complaints and to advise workers of their rights.

It is exciting that the Division could offer an intake system to support workers in enforcing their rights. The Division should account for existing legal assistance being offered to paid care workers and incorporate these existing systems into the Division's intake infrastructure. At NDWA, for instance, we have been coordinating a legal clinic that assesses paid care workers' and housecleaners' claims, connects them with legal service providers, and provides support in filing complaints with various enforcement agencies. Starting this month, we will have DCA staff on-site to take paid sick complaints.

Scaling up these enforcement efforts and raising standards across this industry will require investment from all stakeholders, in particular creative, long-term partnership between government and community groups. I suggest that the City Council look to the New York City Family Justice Centers, a project of the Mayor's Office to Combat Domestic Violence, as a model of the type of inter-agency collaboration and government partnership with community groups and legal services that will be necessary to reach this dispersed workforce at scale and meaningfully raise standards in the industry. The Family Justice Centers are one-stop-shops for legal and social services for domestic violence survivors. The centers receive funding from the United States Department of Justice and New York State and comprise an institutionalized partnership between six City agencies and over 30 community organizations.

Imagine a place where a paid care worker—or perhaps, under the Office Labor Standards, any low-wage worker—could access information about their rights and benefits, speak with a legal service provider, file a complaint for paid sick leave, apply for an Individual Taxpayer Identification Number, and get their CPR certification. One in seven low-wage workers in New York City is a homecare worker. That does not include the tens of thousands of childcare workers who this Division would also serve. This workforce is extremely dispersed and hard to reach and the particularities of the industry make it so workers often require more time and support to get to the point of being able to take legal action to enforce their rights. It will be essential for the Division to partner closely and creatively with existing community groups and service providers in order to significantly scale up enforcement of workers' rights in this industry.

1199SEIU
United Healthcare Workers East

Testimony of
Helen Schaub
New York State Director of Policy and Legislation
1199SEIU United Healthcare Workers East
Int. No. 1084

1199SEIU United Healthcare Workers East represents 70,000 home care workers in New York City. These dedicated caregivers provide assistance to seniors and people with disabilities so that they can remain living independently in their own homes. This assistance includes reminding clients to take medication, preparing hot, nutritious meals, lifting clients from the bed to a wheelchair and many other tasks. They are employed by Home Care Services Agencies licensed by the State Department of Health and funded by Medicaid, Medicare and private insurers and individuals.

Despite their dedicated work, and the value that they produce for the healthcare system in helping reduce unnecessary nursing home and hospital costs, home care workers have been an exploited workforce. They have struggled to survive on poverty wages with few benefits. Unscrupulous employers have failed to follow labor laws on minimum wage, overtime and paid time off as well as regulations regarding training and the release of certificates which allow workers to seek other employment. Because workers are isolated in individual workplaces, it can be difficult for them to learn of and exercise their rights.

Over the past thirty years, as this industry grew exponentially, 1199SEIU home care workers have organized to change this situation. They won union representation and bargained for contracts employer by employer, and then banded together to advocate for increased funding from contractors and the state and federal governments. Over the years, they were able to establish a health benefit fund providing low-cost comprehensive benefits, an education fund which provides workers with the ability to earn certificates and degrees and advance in the health professions, and the first-in-the-nation pension fund for home care workers.

In just the past five years, these courageous leaders achieved the Wage Parity Law at the state level, setting minimum compensation for workers on Medicaid cases in New York City at $14.09 per hour. They were instrumental in the Fight for $15 and will see their hourly wages rise by 50% over the next three years while maintaining their hard-won benefits and paid time off. And because of efforts nationally by our Union and others, the US Department of Labor finally reversed the discriminatory exclusion of home care workers from the Fair Labor Standards Act.

These important policy achievements are not only benefitting workers and their families, they are improving the quality of care for seniors and people with disabilities by reducing turnover and ensuring that experienced, qualified home care workers can remain in the career they love.

We applaud the New York City Council's recognition of this important workforce through the proposed legislation to create the Division of Paid Care under the Office of Labor Standards. If the legislation is passed and the division is established, we look forward to coordinating closely with the staff to ensure that all of New York City's home care workers are informed of their rights and the opportunities for training and other workforce supports that may be available to them.

The information that is received through the complaint hotline and other outreach could prove particularly valuable for enforcement of labor and other relevant laws. For example, the wage parity law prohibits the spending of Medicaid dollars for hours of care for which the worker is not paid the required level of compensation. But because some of this compensation can be provided through benefits, it can be difficult for an individual worker to understand from their paycheck whether their employer is complying with the law. The Division of Paid Care could work with the State Office of the Medicaid Inspector General as well as the State Department of Labor and the Department of Health to refer cases where employers are suspected of not paying according to the wage parity law.

We have only one concern about the legislation as proposed. The list of topics for research in 6(c)(1) is very specific and somewhat limited. While all of these topics are important, there are other equally important topics under the broad areas of worker and patient rights, qualifications of service providers and the structure of the industry including financial incentives. While it is true that there is a catchall "any other topic deemed relevant," it stands to reason that any topics spelled out in legislation would be prioritized. We recommend broadening the list of topics to general areas and allowing the Division of Paid Care to engage stakeholders in a discussion of priority areas for research.

Finally, while we came to discuss Int. 1084 in more detail, I would like to express our Union's support for Int. 1081 and Res. 993 and applaud the Council's advocacy for unpaid caregivers as well.

NATIONAL
EMPLOYMENT
LAW
PROJECT

TESTIMONY

Testimony of Sarah Leberstein

National Employment Law Project

Int. No. 1084-2016: Establishment of a Division of Paid Care

Hearing before the New York City Council Committee on Civil Service and Labor jointly with the Committee on Aging and the Committee on Finance

April 11, 2016

Sarah Leberstein
Senior Staff Attorney

National Employment Law Project
75 Maiden Lane, Suite 601
New York, NY 10038

(212) 285-3025 x313
sleberstein@nelp.org

The National Employment Law Project is a non-profit, non-partisan research and advocacy organization specializing in employment policy. We are based in New York with offices across the country, and we partner with federal, state and local lawmakers on a wide range of workforce issues. Across the country, our staff is recognized as policy experts in areas such as unemployment insurance, wage and hour enforcement, minimum wages, and workplace protections for low-wage workers.

NELP's work has long included a special focus on improving conditions for home care and domestic workers. Among other projects, NELP has played a critical role in campaigns to pass Domestic Worker Bills of Rights in several states and to extend federal minimum wage and overtime rights to home care workers. We have also researched and documented workplace conditions and incidence of wage theft in these sectors. Through our work, we have become acutely aware of the overwhelming need to not only raise workplace standards for workers who have historically been excluded from the protection of key laws, but to ensure that workers know about and can effectively enforce those rights, and especially to cement newly-won rights.

NELP testifies today in support of Int. No. 1084 which would establish a new Division of Paid Care within the Office of Labor Standards. Staffed by a coordinator and an advocate, the Division would create and disseminate educational materials to domestic and home care workers on their rights, the services, available to them, and their options for redressing workplace violations. Because these two overlapping workforces labor in uniquely isolated workplace, and because the industries are shaped by idiosyncratic funding and regulatory regimes, a dedicated staff, well-versed in has high potential to address pervasively low standards and improve workers' lives. Boosting job standards and stabilizing the workforce is not only the right thing to do for workers; it will also be a smart investment in workers' families and communities, who count on workers' wages, and in the services on which tens of thousands of New Yorkers rely to live independently, or support a loved one so they may work and participate in the community.

This reform is desperately needed now for the following reasons:

I. Care workers suffer from persistently low wages and high rates of workplace violations.

A. A report conducted by the National Domestic Workers Alliance from 2011-2012 found that nannies earned an average of $11 per hour.[1]

B. According to research by PHI, in 2014, personal care aides in New York earned a median hourly wage of $10.98. Home health aides' median hourly wages were $10.37.

C. Care workers' low wages are compounded by a high incidence of wage theft. Their physical isolation in private homes, makes them less likely to be able to exercise their rights or negotiate for decent standards, and placing them at unique risk of abuse. Working without Laws,[2] a landmark NELP-led survey of 1,432 low-wage workers in in New York City, found that workers employed in private households experienced especially high rates of wage and hour violations: 37.5% of workers employed in this industry experienced a minimum wage violation (in the week before the survey); 84.6% experienced an overtime violation; 76.4% worked before and/or after their scheduled shifts without being paid for that time; 81.3% experienced a meal break violation.

D. The same survey found that 8.4 % of home care workers suffered a minimum wage violation; 82.9% experienced an overtime violation; 86% worked before and/or after their scheduled shifts without being paid for that time; 83.7% experienced a meal break violation.

E. A companion report, Broken Laws, Unprotected Workers,[3] found that when workers complained about their working conditions or tried to organize a union, employers often responded by retaliating against them, and many workers never made complaints in the first place, often because they feared retaliation by their employer. One in five workers reported that they had made a complaint to their employer or attempted to form a union in the last year. Of those, 43 percent experienced one or more forms of illegal retaliation from their employer or supervisor, such as being fired or suspended or receiving threats to cut pay or call immigration authorities, Another 20 percent of workers reported that they did not make a complaint to their employer during the past 12 months, even though they had experienced a serious problem such as dangerous working conditions or not being paid the minimum wage. Half were afraid of losing their job, 10 percent were afraid they would have their hours or wages cut, and 36 percent thought it would not make a difference.

F. Workers with full-time, full-year work schedule, lose, on average, an estimated $2,634 annually due to the workplace violations summarized above.[4] These lost wages depress family income, and siphon money from their communities. Low pay and high rates of wage theft is also a threat to city revenues, in the form of lost tax revenues and heightened need for city services.

II. Major shifts in both labor and health care policy have the potential to strengthen the City's care systems, but the City must intervene now to ensure workers and consumers benefit from these changes.

A. Numerous reforms hold the potential to drastically improve job standards and alleviate the persistent wage theft that have long plagued the City's large and growing caregiver workforce, including the passage of the Domestic Worker Bill of Rights in 2010, the New York Wage Parity Law, passed in 2011 to raise and equalize wage rates and benefits for Medicaid-funded Home Health Aides, and the extension of federal minimum wage and overtime rules to almost all home care workers,[5] and

State minimum wage increases. New York State's transition to Managed Care has created disruptions for both workers and consumers, even as it aims to strengthen New York's home care system, as some home care providers have attempted to curb costs by illegally reducing services or through other changes to services and schedules. Many workers are likely unaware of the full range of changes taking place, are not well-equipped to evaluate whether home care agency employers are fully complying with Wage Parity requirements, especially the requirement to provide benefits at a certain level, and could lose their eligibility for critical housing, child care, medical and other benefits even as their wages rise.[6] And, because home care and domestic often cross the City caring for multiple consumers in a day, they are at risk of losing out on pay for compensable travel time, even as they are burdened with the cost of metrocards. An intervention by the City at this critical juncture could set New York City's home care system and the domestic work industry on the path towards a more stable future with improved standards for both workers and those they serve.

B. On Demand Companies using an app- or internet-based platform to connect consumers to services employ only a small percentage of the workforce, but they are growing rapidly and have received a great deal of attention from policymakers and the public. Some on-demand companies have come under fire for misclassifying workers as independent contractors, denying them the benefit of workplace protections that apply only to "employees" and shifting tax burdens to workers,[7] while others have taken important steps towards establishing and publicizing good employment practices.[8]

C. Recent policy and enforcement reforms have helped shine a spotlight on and improve conditions for car wash workers, nail salon workers and others. The huge size of the City's home care workforce, numbering around 150,000 – around 1 in every 7 low wage workers in the City – and the anticipated burgeoning need for more workers to meet the demand, militates in favor of increased scrutiny on the City's home care industry as well.

III. By prioritizing rights education and enforcement, collaboration with workers' rights organizations, and coordination with relevant City and state agencies, the Office of Paid Care can achieve deliver real change to care workers.

A. As explained above, while home care workers and domestic workers have suffered the ill effects of decades of exclusion from core workplace rights, recently-enacted labor reforms have the potential to put them on more equal footing with other workers, and to boost rights and wages. Investing staff and resources into a mass public education and outreach campaign just as the laws are being implemented can help ensure these policy reforms take hold. Equally important will be supporting workers' ability to redress legal violations. NELP's experience working with home care and domestic workers has shown us that overwhelming numbers of workers experience a violation of wage and hour or other workplace laws, but yet few seek assistance or effectively resolve their issues. Home care and domestic workers face unique barriers to enforcing their rights: their physical isolation makes it less likely that they will get support from other workers; they are especially susceptible to retaliation by employers, who can explain away changes to work schedule or terminations through claims that the care recipients' needs have changed; and they may fail to take action out of a reluctance to disturb often close personal relationships with care recipients. Workers who reside on the employer's premises may also fear homelessness. And some home care workers may not be in regular contact with the companies sharing employer roles, complicating enforcement efforts. The Office of Paid Care should prioritize an education and enforcement program that recognizes and responds to these challenges with the goal of removing barriers to workers' redress of their rights.

B. To help implement a truly successful education and enforcement program, the Office of Paid Care should collaborate with the City's domestic and home care worker organizing and advocacy groups that have already made huge inroads into educating and mobilizing these workforces to improve and protect rights. These organizations have valuable experience, expertise in reaching workers, and specialized skills – like language capacity, and a high level of trust in the communities in which they work – that make them indispensable partners for a new Office. Contracting with domestic and home care worker organizations would help the Office to maximize its resources and increase its ability to rapidly and effectively connect with workers.

C. The Office of Paid Care should also coordinate its activities with the city and state agencies with ties to workers and ability to effect industry conditions. The Office of Paid Care should coordinate with the Office of Immigrant Affairs to protect the many immigrant workers in these sectors from unjust retaliatory action by employers. In addition to working with labor enforcement agencies, the Office of Paid Care should also coordinate with the city and state agencies that, through their role as payors for home care and childcare services, and licensors of certain agencies, influence pay rates and determine which employers may stay in business. The New York State Department of Health helps to enforce the State's Wage Parity requirements and can help hold Medicaid-funded entities accountable for labor conditions in their workforces. City agencies that contract with private agencies to deliver public-funded care can also be important partners in ensuring public funds promote good workplace standards.

D. Finally, the Office of Paid Care should aim to uncover, understand, and uphold labor standards in nonstandard work structures by: addressing independent contractor and subcontracting abuses in the on-demand economy, as well as similar abuses that have long persisted among domestic and home care referral agencies and "registries", home care subcontractors and the agencies they contract with, and other segments of the industry; recognizing the on-demand and conventional businesses that have adopted good employment models; encouraging technological innovation that supports workers' and consumers' rights.[9]

Conclusion

The National Employment Law Project strongly supports this effort to establish an Office of Paid Care.

Thank you very much for giving me the opportunity to speak today. I am happy to answer any questions now, or at any time after the hearing.

---

[1] Linda Burnham, et al, Home Economics: The Invisible and Unregulated World of Domestic Work (2012) http://www.domesticworkers.org/sites/default/files/HomeEconomicsEnglish.pdf.

[2] Annette Bernhardt, et al., Working without Laws: A Survey of Labor and Employment Law Violations in New York City (2008), http://www.nelp.org/content/uploads/2015/03/WorkingWithoutLawsNYC.pdf.

[3] Annette Bernhardt, et al., Broken Laws, Unprotected Workers: Violations of Employment and Labor Laws in America's Cities (2009) http://www.nelp.org/content/uploads/2015/03/BrokenLawsReport2009.pdf?nocdn=1

[4] Id.

[5] See, for example, NELP webpage on the fight for fair wages for home care workers, at http://www.nelp.org/campaign/implementing-home-care-reforms/.

[6] Steve Dawson and Carol Rodat, The Impact of Wage Parity on Home Care Aides (PHI 2014), http://phinational.org/sites/phinational.org/files/research-report/phi-benefitcliffs-20140623.pdf.

[7] See, for example, Rebecca Smith and Sarah Leberstein, Rights on Demand: Ensuring Workplace Standards and Worker Security in the On-Demand Economy (NELP, 2015), http://www.nelp.org/publication/rights-on-demand/.

[8] NELP Fact Sheet, Employers in the On-Demand Economy: Why Treating Workers as Employees is Good for Business, (March 2016) http://www.nelp.org/content/uploads/Fact-Sheet-Employers-in-the-On-Demand-Economy.pdf.

[9] See, for example, Sarah Leberstein, Irene Tung & Caitlin Connolly, Upholding Labor Standards in Home Care: How to Build Accountability in America's Fastest Growing Jobs (2015), http://www.nelp.org/publication/upholding-labor-standards-in-home-care-how-to-build-employer-accountability-into-americas-fastest-growing-jobs/.

caringkind The Heart of Alzheimer's Caregiving

360 Lexington Avenue, 4th Fl.
New York, NY 10017
caringkindnyc.org
F: 212-697-6037

24-hour Helpline
P: 646-744-2900
helpline@caringkindnyc.org

New York City Council

Joint Committee Hearing

Committee on Aging, Council Member Margaret Chin, Chair

Committee on Civil Services and Labor, Council Member I. Daneek Miller, Chair

Monday, April 11, 2016

Testimony by Jed A. Levine, Executive Vice President, Director of Programs and Services, CaringKind, The Heart of Alzheimer's Caregiving

Formerly known as the Alzheimer's Association, NYC Chapter

Thank you for the opportunity to discuss the issues of Caregiving in New York City. I am Jed Levine, Executive Vice President and Director of Programs and Services at CaringKind. For over thirty years, we operated as the New York City Chapter of the Alzheimer's Association. On December 1, 2015 we disaffiliated from the National Association and returned to our roots as an independent charity. Only our public name changed. We remain the only organization in New York City singularly focused on care and support for individuals with Alzheimer's and related disorders and their families and paid 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 5.2 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 66 seconds a person in the United States is diagnosed with Alzheimer's disease and we expect by 2030 there will be 7.1 million people age 65 and older living with Alzheimer's. The financial ramifications of the disease are daunting and currently cost America $236 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 gradually no longer able to work, enjoy lifelong hobbies or social life. It is an eventually terminal illness. 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.

CaringKind is on the front lines every day providing a wide variety of educational and support programs, including over 90 monthly support groups, a Wanderer's Safety Program, a 24-hour

Helpline and social work 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 other professionals to better care for persons with dementia. A major focus for our organization 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 increase by nearly 50 percent over the next 25 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.

In 2015, more than 15.9 million caregivers provided an estimated 18.1 billion hours of unpaid care to PWDs nationwide. This care is valued at $221 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.

At CaringKind we have worked with 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 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 CaringKind 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 does not have the time or energy to search for assistance.

We also know that many families are dependent on the help of paid home care workers, many of whom have had little or no training in dementia care. We have been conducting a nationally recognized dementia care training program for over 25 years, and have learned a lot about how to improve knowledge, change practice and improve the care of persons with dementia, as well as providing the workers with a sense of pride and as the data show us, maximize the chance that they will stay in the field of dementia home care. Many of the home care workers we train are independent agents, and we have created *TogetherWeCare.com*, an online matching program to help them find employment and to help families find trained aides. We have long been advocates for fair treatment of home care workers, who often work in isolated, stressful situations without support.

We support the legislation to create a division of paid care which would provide home care with access to information about their rights, where to find low cost health insurance, and how to proceed with grievances.

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 CaringKind's 24-hour Helpline.
- Fund Caregiver Support Services at $4 Million, consistent with the recommendation from the Council and supported by LiveOnNY. 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.

CaringKind deeply appreciates the commitment of the Committees of Aging and Civil Services and Labor to improving the lives of New York's family and paid caregivers. And we congratulate Speaker Mark-Viverito and Council Members Chin, Rose, Palma, Rodriquez, Rosenthal and Ulrich for their support of Int. 1081-2016 which would create a comprehensive plan to address the needs of informal and family caregivers. CaringKind stands ready to provide expert guidance and assistance in considering these matters.

JASA

New York City Council
Committee on Aging and Committee
Jointly with the Committee on Civil Service and Labor
Int. no: 1081, Int. no.1084, and Res. No. 993

Monday, April 11, 2016

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, and I. Daneek Miller, Chair of Civil Service and Labor Committee for holding this important hearing on addressing the needs of informal 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 older adults as they age in their homes and communities. A critical component in sustaining the frailest among us, is the role of informal and formal caregivers. As such, JASA strongly supports Intros 1081, 1084, and Resolution 993, which call attention to the needs of caregivers, informal and formal, and recognizes the tremendous financial cost of providing care.

Resolution 993 states statistics relating to the informal caregivers we are discussing today. With AARP estimating that "at any given time during the year, over four million family caregivers in New York State are providing unpaid care for a loved one", and "nearly six in ten caregivers are working while providing elder care to family members" according to State Family Caregiver Council. Clearly there is a need to assist people in their ability to provide this much needed, unpaid service. Everyone in this room knows someone who is serving as an informal caregiver, and I imagine many of us in the room fit that bill as well. A state tax-credit for caregiving is long overdue.

Through the development of a comprehensive survey of caregivers, Int 1081 will formalize what we already know about caregivers and help the City to create an action plan for addressing the growing need in New York City for supportive services and programs of assistance. Int 1084 will further support formal caregivers in providing them with concrete services and a City-based advocate. With the numerous changes to Medicaid funded home-care, and the challenges facing home care agencies and their staff, a designated

Division of Paid Care within the Office of Labor Standards will provide clarity on legal rights, changes in mandates, and links to important information for this growing sector of workers.

Since 2006, JASA has operated a DFTA funded Caregiver Respite program in South Brooklyn. Through this program, JASA assists more than 1000 individuals each year, helping family caregivers with such services as in-home and group respite care, individuals 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 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 evidence-based activities. 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 the brief pilot, JASA Connections successfully identified and matched volunteer-mentors and family caregivers. 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.

We appreciate the DFTA funding that enables JASA to offer a range of services to support caregivers through the Brooklyn Caregiver Respite Program. We have also sought to develop innovative initiatives to expand the scope of services and client "reach." These initiatives need modest financial support from the City to implement them in a more sustainable and comprehensive manner. For example, funding for a coordinator to recruit, train, and supervise volunteer-mentors in an ongoing way would be helpful. 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, an openness to proposals to fully fund proven programs and new initiatives, and that appropriate City funds are dedicated to see the proposed legislation fulfilled.

Thank you.

Molly Krakowski
Director of Legislative Affairs
JASA
212 273-6260
mkrakowski@jasa.org

LiveOn NY
Making New York a better place to age

New York City Council
Joint Committee Hearing
Committee on Aging, Council Member Margaret Chin, Chair
Committee on Finance, Council Member Julissa Ferreras-Copeland, Chair
Committee on Civil Services and Labor, Council Member I. Daneek Miller, Chair
Monday April 11, 2016

Testimony by Bobbie Sackman, Director of Public Policy, LiveOn NY

LiveOn NY is dedicated to making New York a better place to age. Founded in 1979, with a membership base of more than 100 organizations ranging from individual community-based centers to large multi-service organizations, LiveOn NY is recognized as a leader in aging. LiveOn NY's membership serves over 300,000 older New Yorkers annually and is comprised of organizations providing an array of community based services including caregiving support services, elder abuse prevention and victims' services, case management for homebound seniors, multi-service senior centers, congregate and home-delivered meals, affordable senior housing with services, transportation, NORCs and other services intended to support older New Yorkers. LiveOn NY connects resources, advocates for positive change, and builds, supports and fosters innovation. Our goal is to help all New Yorkers age with confidence, grace and vitality.

LiveOn NY is appreciative that the Committees on Aging, Finance and Civil Services and Labor have convened this hearing. On December 9, 2014, LiveOn NY testified at a City Council Committee on Aging hearing on Caregiving and recommended that 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. LiveOn NY testified that this data would assist the city in planning for the growing number of caregivers and to make these thousands of caregivers visible. LiveOn NY applauds Speaker Melissa Mark-Viverito and Council Members Chin, Rose, Palma, Rodriguez, Rosenthal and Ulrich for their leadership by supporting Int. 1081-2016 which calls for a survey and comprehensive plan to address the needs of informal caregivers.

Given the broad impact of caregiving and the increasing number and diversity of caregivers and older adults, it is time for the city 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 21st 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.

Because the needs of caregivers will only continue to grow, LiveOn NY applauds City Council for addressing this issue and proposing this legislation. LiveOn NY supports Int. 1081-2016 and respectfully offers the following recommendations.

Recommendations:

1. **The survey should include important demographics on caregivers** including but not limited to neighborhood demographics, income, immigrant/diversity, workplace issues, age, 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 caregivers, most of which are women, visible.
2. **DFTA should work with and involve community based organizations, particularly those currently providing caregiving services, in each step of this process in development, and advocates.** This includes development of the survey and questions, how to disseminate the survey, understanding access considerations such as translation of the survey and where and how to provide to the survey. This input will be invaluable to ensure the city collects the most pertinent information in the most efficient and effective method. DFTA should also consult other city, state and national organizations such as AARP and the National Caregiving Alliance who have vital statistics, information and recommendations on caregiving issues. DFTA should also work with other groups such as the business community, labor unions, employers, business groups, retirees and other groups that have valuable information about caregivers' needs.
3. **DFTA should work with and involve community based organizations when developing the Comprehensive Plan.** Once data is collected, community based organizations should be involved in formulating the Comprehensive Citywide Caregiving Plan during each phase.
4. **As part of the Comprehensive Plan, NYC must establish baselined caregiver support funding at least $~~3~~4 million for FY17** – The only funding currently available for caregiver support services is $4 million through the federal Older Americans Act. This funding has been stagnant for many years. It is well past time that NYC establish city funding to support caregivers. Caregivers often don't inform their employers of their caregiving responsibilities or all the details of their caregiving for fear of losing a promotion or a job. Women caregivers sometimes leave the workforce, work part-time or get stuck in a job unable to be promoted. Providing supportive services for the caregiver is key to the caregiver's 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, adult day care, 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.

5. **Fund aging services** – These services include case management, home care, senior centers, social adult day care and home-delivered meals are all provided by the DFTA funded community-based aging services network and support family caregivers by providing services for their loved one. Universal adult day care, including social adult day care for those above the Medicaid level, would go a long way to establish a citywide community-based network of support services for both older adults and caregivers.
6. **Support state legislation to expand workplace flexibility** – LiveOn NY applauds the recent state passage of paid leave for caregivers which includes caring for an older adult. It is vital for the city to ensure caregiving for older adults is included in city initiatives that provide workplace flexibility for caregiving. Support from City Council and the de Blasio administration to call on the state pass state legislation which includes language regarding caregivers for older adults and workplace flexibility. Addressing caregiving across the lifespan is essential and is the 21st century workforce issues, especially for women.
7. **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.
8. **The Comprehensive Plan should include a Public Education Campaign and funding** to increase awareness of caregiving and the resources available in the City.

LiveOn NY thanks City Council and the Administration for recognizing the needs of caregivers and looks forward to working with you on this important issue.

Hand in Hand
THE DOMESTIC EMPLOYERS NETWORK

Julie F. Kay, April 11, 2016
Testimony in Support of Into 1084, Creation of NYC Division of Paid Care

I submit this testimony today as a member of the so-called "sandwich generation." For six years I provided care simultaneously for 2 young children and for my mother who suffered and eventually died from Alzheimer's disease. When I talk with friends and others who are now similarly "sandwiched" with caregiving, our conversations center on how absolutely vital it is to have domestic workers to rely upon for these difficult and crucial caretaking years.

As a women's rights attorney, I am also well aware of the strain such caregiving places upon women who are balancing work and family responsibilities. When a caregiving crisis hits at home and there is insufficient support, the negative effects inevitably reverberate on a person's workplace performance. Not only is it fair to establish employment standards and practices that help strengthen the profession of caregiving, but it is smart as well.

I believe that despite our best intentions, employers often lack the know-how to be fair employers of professional caregivers. Employers may inadvertently overlook fair wages and employment practices, or fail to take them seriously because community norms that neglect the importance of professional caregiving work.

By establishing the Division of Paid Care under the Office of Labor Standards in the Department of Consumer Affairs, the NYC Council would bring us forward toward developing employment standards and basic legal protections for this vital part of New York City's workforce. Despite New York State's success as the first state to have a Domestic Workers Bill of Rights, there is still much work to be done to raise the awareness of domestic employers' obligations.

As a former employer of several child and elder care caregivers, I strongly believe that establishing the Division of Paid Care would facilitate the design and implementation of much needed city-level policies and programs applying to paid care workers. This action would provide essential information to caregivers and their employers, going well beyond the informal, piecemeal system that we rely on now.

Moreover, this Division could gather data to shine a light on the demographics of paid care workers and their clients in the city, the practices of home care referral and placement agencies, and allow for greater collaboration with worker centers and community based organizations that can bridge the gaps between employers and caregivers.

I am pleased to be a member of Hand in Hand and the New York-based community of employers and consumers who are dedicated to improving the industry for both workers and the families and individuals they serve. Through some of the most difficult caretaking years, my family relied upon quality caregivers and I am most grateful for their skill, professionalism and the stability they provided. I am pleased to support this initiative to ensure that domestic workers have the support they need to provide the best care for the people and families that employ them.

For these reasons I would also encourage the Council to support Int No. 1081 Comprehensive Plan to Address the Needs of Informal Caregivers that would require the city to do a survey of informal caregivers and Resolution 993, calling upon the New York State Legislature to introduce and pass, and the Governor to sign, legislation to expand the New York City child care tax credit.

Thank you for your attention to this matter.

SNAP
Services Now for Adult Persons, Inc
YOUR KEY TO AGING SERVICES

SERVICES NOW FOR ADULT PERSONS, INC.
80-45 Winchester Boulevard, Building # 4, CBU #29
Queens Village, New York 11427
(718) 454-2100 ~ (718) 740-4999
SNAPqueens@aol.com ~ www.SNAPqueens.org

EXECUTIVE BOARD
CHRIS PANELLINO
CHAIR

NOREEN MURPHY, RN
VICE CHAIR

COREY BEARAK, ESQ.
TREASURER

SUSAN COHEN
RECORDING SECRETARY

BOARD MEMBERS
SUSAN ARAKAL, RN
JACQUELINE BOYCE
ANN M. CARROZZA, ESQ.
F. JACOB CHERIAN
FLORENCE KATZ, MSW
RONALD SCHWARTZ, ESQ.
SUSAN SEINFELD, MSW
MINDY STERN, SPHR
FRANK ULAKY
LARCENIA WALTON

PAOLA MICELI, MPA
CEO/PRESIDENT

MARIAN LEWEK, LMSW
CHIEF OPERATING OFFICER

TESTIMONY

JOINT CITY COUNCIL COMMITTEE

HEARINGS

MONDAY, APRIL 11, 2016

~ ~ ~ ~ ~

BERNADETTE JOSEPHS, LMSW

DIRECTOR, CAREGIVER PROGRAM

GOOD MORNING DISTINGUISHED MEMBERS OF THE COMMITTEES ON CIVIL SERVICE AND LABOR, AGING AND FINANCE. THANK YOU FOR CONDUCTING THIS HEARING THIS AFTERNOON. MY NAME IS BERNADETTE JOSEPHS. I AM THE DIRECTOR OF SERVICES NOW FOR ADULT PERSONS, INC'S (SNAP) CAREGIVER PROGRAM.

SNAP IS A SOCIAL SERVICE AGENCY THAT PROVIDES A VARIETY OF SERVICES FOR OLDER ADULTS IN QUEENS.THESE SERVICES ARE GEARED TOWARDS REDUCING ISOLATION, IMPROVING QUALITY OF LIFE AND ASSISTING IN HELPING OLDER ADULTS REMAIN SAFE AT HOME AND IN THE COMMUNITIES THEY LOVE, AS THEY AGE IN PLACE. SNAP ALSO OPERATES A GROWING CAREGIVER PROGRAM FOR INDIVIDUALS CARING FOR A LOVED ONE OR FRIEND.

IN THE COURSE OF DIRECTING SNAP'S CAREGIVER PROGRAM I HAVE COME TO RECOGNIZE THAT FAMILY CAREGIVERS COME FROM ALLWALKS OF LIFE AND I HAVE FOUND THAT PEOPLE DEFINE FAMILY IN MANY DIFFERENT WAYS. CAREGIVERS FOR EXAMPLE INCLUDE: SPOUSES, PARTNERS, ADULT CHILDREN, OTHER FAMILY MEMBERS, FRIENDS, AND/OR NEIGHBORS WHO PROVIDE UNPAID ASSISTANCE TO A LOVED ONE WITH A CHRONIC ILLNESS. WITHIN THE ELDERLY POPULATION, THE FASTEST GROWING AGE COHORT ARE THOSE WHO ARE 85 YEARS OF AGE AND OLDER. OUR EXPERIENCE FINDS THAT THE NUMBER OF PEOPLE CARING FOR AN OLDER ADULT RELATIVE OR FRIEND IS GROWING AS IS DEMONSTRATED BY AN INCREASE IN CAREGIVER PROGRAM CASELOADS FROM 35 TO 90 SINCE THE PROGRAM BEGAN IN 2003.

CAREGIVING IN NEW YORK CITY AND ACROSS THE NATION IS ONE OF THE MOST CRUCIAL ISSUES OF OUR DAY. AMERICAN FAMILY LIFE HAS CHANGED DRAMATICALLY OVER TIME. THERE IS NOW A GREATER NEED FOR TWO INCOMES TO MAKE ENDS MEET WHILE SINGLE INCOME HOMES ARE MORE PREVELANT. FAMILY CAREGIVERS ARE IN A CONSTANT STRUGGLE TO BALANCE WORK AND CAREGIVING RESPONSIBLITIES. ACCORDING TO A RECENT NATIONAL SURVEY, 1 IN 5 CAREGIVER RETIREES LEFT THE WORKFORCE EARLIER THAN THEY PLANNED DUE TO CAREGIVER REPSONSIBILITIES. 7 IN 10 HAD TO MAKE WORK ADJUSTMENTS WHICH INCLUDED CUTTING BACK ON WORKING HOURS, CHANGING JOBS OR LEAVING WORK COMPLETELY. LOW INCOME WORKERS, WOMEN AND MINORITIES WERE THOSE MOST LIKELY TO REDUCE WORK HOURS OR LEAVE WORK COMPLETELY. WOMEN ARE THE ONES MOST IMPACTED FINANCAILLY SINCE THEY MAKE UP THE MAJORITY OF CAREGIVERS. THE TOTAL INDIVIDUAL AMOUNT OF LOST WAGES DUE TO LEAVING THE LABOR FORCE EARLY AND/OR REDUCING HOURS OF WORK BECAUSE OF CAREGIVING RESPONSIBILITIES EQUALS $142,693.THE TOTAL ESTIMATED AGGREGATE LOST WAGES, PENSION, AND SOCIAL SECURITY BENEFITS OF ADULT CHILDREN CAREGIVERS IS NEARLY $ 3 TRILLION. THE ESTIMATED IMPACT OF CAREGIVING ON LOST SOCIAL SECURITY BENEFITS IS $131,351.

THIS SPEAKS TO ISSUES THAT CAN BE ADDRESSED IN A VAREITY OF WAYS:

- FLEXIBLE WORK ARRANGEMENTS AND PAID FAMILY LEAVE IS ONE WAY OF ADDRESSING CAREGIVER NEEDS.

- CONSIDER THE EXPANSION OF THE NYC CHILD CARE TAX CREDIT TO INCLUDE ADULT DEPENDENTS. THIS WILL CREATE AN ADDITIONAL RESOURCE TO HELP ALLEVIATE THE FINANCIAL STRAIN A CAREGIVER FACES AND COULD MAKE THE DIFFERENCE BETWEEN HAVING TO LEAVE THE WORK FORCE OR REMAIN EMPLOYED. IT WOULD HELP TO ALLEVIATE THE HIGH COST OF HOMECARE ENSURING THAT CARE-RECEIVERS ARE TAKEN CARE OF APPROPRIATELY IN THEIR HOMES WHILE INFORMAL CAREGIVERS CAN CONTINUE WORKING KNOWING THEIR LOVED ONE IS SAFE AND CARED FOR. ONE CLIENT IN PARTICULAR COMES TO MIND WHO WAS NOT ONLY CARING FOR HER FATHER WHO HAD DEMENTIA, BUT ALSO HER BROTHER WHO HAD A STROKE AND WAS BED RIDDEN. THIS CLIENT WAS UNABLE TO COVER THE COST OF HOMECARE FOR BOTH HER FATHER AND HER BROTHER. SHE LEFT THE WORKFORCE AS A RESULT AND BECAME THEIR FULL-TIME CAREGIVER. EXPANDING THE NYC CHILD CARE TAX CREDIT TO ADULT DEPENDENTS WOULD HAVE GIVEN HER AN OPPORTUNITY TO MAKE A DIFFERENT CHOICE.

- ESTABLISHING A DIVISION OF PAID CARE WITHIN THE OFFICE OF LABOR & EMPLOYMENT STANDARDS WOULD BENEFIT PAID CARE WORKERS AS WELL AS FAMILIES AND CARE RECEIVERS. BY PROFESSIONALIZING THE HOME HEALTH CARE INDUSTRY, THE QUALITY AND CONSISTENCY OF HOME CARE WORKERS WOULD INCREASE DUE TO THE ADDITIONAL STANDARDS THAT WOULD BE IMPLEMENTED THROUGH THIS OFFICE. PROFESSIONALISM WOULD LEAD TO A GREATER WILLINGNESS AND TRUST IN HIRING HOME CARE WORKERS.

-INCREASED 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 A NURSING HOME AND REPRESENTS THE DESIRE OF THE MAJORITY OF OLDER ADULTS AND THEIR CAEGIVERS. IN ADDITION, SOCIAL ADULT DAY PROGRAMS ARE ON HIGH DEMAND BY MANY WORKING CAREGIVERS. IT IS VERY COSTLY FOR FAMILY MEMBERS WHO'S OLDER ADULTS DO NOT HAVE MEDICAID AND ARE FORCED TO PAY OUT OF POCKET. MODELING SOCIAL ADULT DAY PROGRAMS AFTER THE UNIVERSAL PRE-K PROGRAMS THAT RECEIVE STATE FUNDING WOULD BE A FINANCIAL HELP TO CAREGIVERS.

THE CURRENT CAREGIVER SUPPORT FUNDING COMES THROUGH THE FEDERAL OLDER AMERICANS ACT AND ALLOWS 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 RESPONSIBLITIES. BUDGETS ARE GREATLY LIMITED. IN ORDER TO STRETCH THE CAREGIVING BUDGET AND MEET THE REQUESTS THAT COME IN DAILY FROM CAREGIVERS FOR RESPITE SERVICES SNAP CAN ONLY OFFER RESPITE TWICE A MONTH UP TO A MAXIMUM OF APPROXIMATLY THREE MONTHS. ALSO, THERE IS A 3 TO 6 MONTH WAITLIST FOR THIS SERVICE. ONE CLIENT FOR EXAMPLE WAS A 26 YEAR OLD CAREGIVER, WORKING FULL TIME, CARING FOR HER TERMINALLY ILL MOTHER. ALTHOUGH THE CLIENT'S MOTHER WAS ON HOSPICE, THIS SERVICE DID NOT PROVIDE SUFFICIENT HOME CARE HOURS. THE CLIENT WAS LOOKING FOR ADDITONAL HELP SO SHE COULD KEEP HER EMPLOYMENT AND HER MOTHER COULD REMAIN SAFE AT HOME. SADLY, THE MOTHER PASSED AWAY BEFORE RESPITE SERVICES BEGAN. THIS DEMONSTRATES THAT THE NEED FOR CAREGIVER SUPPORT FAR OUTWEIGHS THE CAPACITY TO PROIVDE SERVICES. IT SHOULD ALSO BE NOTED THAT CAREGIVER SUPPORT **AND** AGING SERVICES SUCH AS CASE MANAGEMENT HOME DEVLIERED MEALS, HOME CARE (EISEP SERVICES) AND SOCIAL ADULT DAY PROGRAMS WORK HAND IN HAND TO PROVIDE SUPPORT FOR BOTH THE CAREGIVER OF AN OLDER ADULT CARERECEIVER.

ON A FINAL NOTE, WHEN DEVELOPING THE SURVEY TO ASSESS EXISTING INFORMAL CAREGIVER SERVICES AND IDENTIFY THE NEEDS OF INFORMAL CAREGIVERS, SNAP RECOMMNEDS THAT IT BE DEVELOPED IN CONJUNCTION WITH COMMUNITY BASED ORGANIZATIONS WHO ARE PRESENTLY OPERATING CAREGIVER PROGRAMS THROUGHOUT NEW YORK CITY AND WHO ARE FAMILIAR WITH THE CONTINUOUS CHANGES AND NEEDS OF CAREGIVERS. THIS COLLABORATION WOULD ALLOW COMMUNITY BASED ORGANIZTIONS TO BRING A WEALTH OF INSIGHT IN REGARD TO THE DEMOGRAPHICS OF CAREGIVERS CAPTURING THE DIVERSITY, BREADTH AND WIDTH OF THOSE WHO IDENTIFY AS INFORMAL CAREGIVERS. THIS WILL HELP TO DEVELOP QUESTIONS THAT TRULY CAPTURE WHAT IS AT STAKE FOR WORKING AND NON-WORKING CAREGIVERS AND WILL CREATE AN EFFECTIVE TOOL THAT WILL HELP TO IMPLEMENT APPROPRIATE SERVICES

I APPRECIATE HAVING THE OPPORTUNITY TO SPEAK TO ALL OF YOU TODAY AND KNOW THAT YOU WILL WORK DILIGENTLY ON BEHALF OF CAREGIVERS IN NEW YORK CITY AND THROUGHOUT THE STATE.

Hand in Hand
THE DOMESTIC EMPLOYERS NETWORK

Good afternoon, my name is Ilana Berger, and I am happy to offer my testimony in support of the creation of the NYC Division of Paid Care (Intro 1084).

I am the Director of Hand in Hand, the Domestic Employers Association. Hand in Hand is a national network of employers of nannies, housecleaners and home attendants who believe that dignified and respectful working conditions benefit worker and employer alike. We support employers to improve their employment practices, and to collaborate with workers to change cultural norms and public policies in order to bring dignity and respect to domestic workers and all of our communities.

I offer my enthusiastic support for the creation of this Division of Paid Care for a number of reasons:

First, the work of this proposed division is so important to New York City's ability to understand the care workforce and to solve the problem of the growing need for care, while creating quality jobs that can raise the floor for many New Yorkers. A recent study by the International Trade Union Confederation shows that investment into the care economy of 2% of GDP in just 7 countries would create over 21 million jobs and help countries overcome the twin challenges of ageing populations and economic stagnation.

On a more person level, at Hand in Hand, I work with hundreds of employers who benefit from the tremendous service that care workers provide. We have learned through our work and our own experiences that the interests of individual families and the workers we employ are more aligned than you might realize. We share a mutual interest in greater recognition for care work and caregiving, leading to more support for this critical workforce and more support for individuals and families to access and afford the care that we need. All of us at Hand in Hand applaud the division for ensuring that there is strong implementation and enforcement for all laws and protections for this valuable workforce, and, we hope, over time, additional work to raise the standards across the care industry. We believe that devoting this type of attention to this workforce, is extremely important. As Ann-Marie Slaughter, President, New America

Foundation says, " Making paid and unpaid care work visible and valuable...in the U.S. and other countries can foster human well-being, build a stronger social network, and ultimately, promote greater economic growth. Bringing the global social, cultural, and policy implications for care out of the shadows will shine a light on the work that makes work possible."

I can speak to this not just because of my job, but because of my own experience. I am a member of the 'sandwich generation' - sandwiched between caring for young children and aging parents. A recent study of the Pew Charitable Trust showed that nearly half (47%) of adults in their 40s and 50s have a parent age 65 or older and are either raising a young child or financially supporting a grown child (age 18 or older). And about one-in-seven middle-aged adults (15%) is providing financial support to both an aging parent and a child.

The financial, emotional and spiritual toll that I and so many of my peers manage because of caring for multiple generations of people we love, is huge. This January, my father passed away, and I spent most of December and January in Boston with him and my mother and sister. Now I still travel to Boston regularly , to help my mom (who just had her knee replaced) and my grandmother, who is 104. I am so fortunate to have an amazing person, Kate, caring for my daughters - Hannah who is 6, and Rosie, who is 3, when I am away, and expect that someday, my sister and I may also need to employ someone to help with our mother (fortunately, she is in great shape now, bionic knee and all.)

I could NOT have been there for my parents, without help for my children. Kate and my partner made it possible for me to be with my father when he passed. I trust Kate completely with my children, and consider the work she does to be among the most important in our society. So many of my friends and peers are in similar situations - and I know that this need will only grow.I cannot imagine a world where we can't figure out a way to provide this caring workforce the fair pay, benefits and respect that they deserve. The Division of Paid Care is a huge forward thinking initiative that can support this growing workforce, and provide benefit to ALL New Yorkers.

As part of my support for this legislation, I want to include a few recommendations.

First, as an employer, and sandwich generation member, I want to speak to the issue of affordability of care. It is important to acknowledge that even with best enforcement, support and legislation, it is still impossible for most individual employers to provide adequate pay, not to mention benefits, because families themselves lack adequate resources. In addition to stronger protections and much higher minimum wage for workers, we also need changes in policy to create affordable care for children, people with disabilities and seniors. While we know that there are limits on what the city can do in the area of care affordability, we hope that this new office will partner with our organizations and other City and State agencies to explore options for providing long-term affordable care across the age spectrum. Hand in Hand is in the process of completing a survey that takes a first look into employers of domestic workers around the state, and their challenges with affordability. This research could contribute to other bodies of research and advocacy conducted on behalf of the Division, and we would be happy to collaborate.

Second, I strongly urge you to be explicit about collaborating with worker centers, community-based organizations and employers organization as a primary strategy for reaching workers and employers.. On the employer end, we know that even with the best laws on the books, in a workforce that is so dispersed - literally household by household - it is a huge challenge to reach employers at scale. Hand in Hand, over the past several years, has developed unique and important insight and experience into how to do this work, and success in reaching thousands of employers. Through our partnership with Care.com and NDWA, we have reached over 90,000 employers nationally who have signed our Fare Care Pledge. Through our My Home is Someone's Workplace campaign, we offer workshops, tools and resources to employers to support them in creating high standard workplaces. We believe that the inclusion of our organization, and others like us, would strengthen the Division's ability to reach employers, and ultimately would contribute to raising the standards for the care workforce in NYC.

The same is true on the worker side- worker centers and CBOs have done tremendous work developing best practices in reaching out and educating workers on their rights. It would be more efficient and effective to partner with these organizations who have already developed successful models, and contract them to do this some of this work to reach specialized populations with whom they have experience working.

Additionally, we urge you to include housecleaners under the scope of the Division's work. While housecleaners do not obviously fall under the category of paid care, we know that there is level of fluidity and continuity between house cleaning and care work. So many of our employers, particularly seniors, who are transitioning from independent living to the a need for some assistance, rely on housecleaners to take on additional care work. We would like to see the Office of Labor standards provide some matching level of attention in its programs and policies to supporting housecleaners.

Finally, this Division will be much more successful with the ongoing input and support of the people who know the industry best - workers, employers and other relevant advocates. I urge you to create an advisory board or other leadership body comprised of these constituencies, and make it a board that has real input and participation in the work of the Division.

Again, thank you for work, and I offer my support, and that of the staff and members of Hand in Hand to Intro 1084, and the creating of a NYC Division of Paid Care. Please feel free to reach out to me at any time if I can be of assistance.

Ilana Berger
Director
Hand in Hand: The Domestic Employer Network
ilana@domesticemployers.org
347.645.4255

Cidadão Global
Local Action Global Rights

Cidadão Global
BRAZILIAN COMMUNITY CENTER

43-12 34TH Avenue, Long island City, NY 11101 – (718) 619-8529

FOR THE RECORD

Testimony to the New York City Council Committee on Civil Service and Labor, Committee on Aging and Committee on Finance's Joint Hearing on:

"Int. 1081- In relation to a comprehensive plan to address the needs of informal caregivers
Int. 1084 - In relation to the establishment of a division of paid care
Res. 993 - Calling upon the New York State Legislature to introduce and pass, and the Governor to sign, legislation to expand the New York City child care tax credit"

Monday, April 11, 2016

INTRODUCTION

Good afternoon and thank you, members of the Committees on Civil Service and Labor, Aging, and Finance. My name is Stephanie Mulcock and I am Executive Director of Cidadão Global, a nonprofit advocating on behalf of Brazilian immigrants in New York City. Cidadão Global appreciates the opportunity to present testimony to the City Council today in support of the creation of the Division of Paid Care.

First, we would like to thank the Committees for providing a forum to have this important discussion. This is an essential step towards finding ways to protect paid care workers in New York City, as well as those who they care for.

Cidadão Global (CG) is dedicated to advocating for the human rights of Brazilian immigrants while strengthening citizen participation and political visibility through fostering leadership development, community organizing, civic engagement, and culture preservation, while providing essential services. CG's programmatic purposes focus on increasing knowledge of rights, increasing economic opportunity, providing a platform to build leaders from within the community, and empowering the most underrepresented members of the Brazilian immigrant community, such as youth and domestic workers.

INCLUDE COLLABORATION WITH COMMUNITY-BASED ORGANIZATIONS

Cidadão Global works with a number of immigrant paid care workers who live and work in New York City. Eighty percent (80%) of the immigrant Brazilian women we serve are paid care workers. They come to us for assistance in cases of wage theft, discrimination, and abuse, all of which are rampant in an industry where the workplace is someone's home.

It is extremely important that the creation of a Paid Care Division include collaboration with community-based organizations because we are at the frontlines of providing the vital assistance that paid care workers need and we are often the first, sometimes the only, service provider they find. Immigrant populations often mistrust city agencies and Brazilian immigrants are no different. Further, there is a lack of resources in Portuguese to assist this population. Cidadão Global is the only community-based organization that provides language specific and culturally appropriate services to immigrant Brazilian domestic workers. A collaboration between the new Division of Paid Care and community-based organizations is vital to support hard-to-reach immigrant populations like Brazilians and prevent them from falling through the cracks.

CONSIDER THE SPECIFIC NEEDS OF IMMIGRANT WOMEN IN SERVICES PROVIDED BY THE DIVISION

A large portion of domestic workers in New York City are immigrant women. Many are also undocumented immigrants. A key issue that keeps many workers from asserting their rights is the belief they do not have labor protections as undocumented workers and the fear of immigration-retaliation by employers. We would like to see close collaboration with the Mayor's Office of Immigrant Affairs to provide other relevant and language accessible information and services to this population.

We encourage the Mayor and City Council to invest in protecting labor rights as a way to empower immigrants and, ultimately, lift immigrant populations out of poverty. We believe that, if immigrant workers in the care industry can be supported by our elected officials and by our government agencies, we will empower our communities to excel and create better care for our loved ones.

FOR THE REC

April 11, 2016

New York City Council

Testimony of Narbada Chhetri, Community Organizer & former Domestic Worker, in Support of Int. No. 1084

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

Namaskaar and Good afternoon! My name is Narbada Chhetri. I am the Director of Organizing and Advocacy at Adhikaar. We are a voice in the Nepali and Tibean speaking community for human rights and social justice. Our programs at Adhikaar are generated from the needs we saw in the community. We organize domestic workers, nail salon workers, gas station workers, and also provide direct services including "English for Empowerment" classes, citizenship classes, wage-theft clinics, healthcare enrollment, and referrals and language support when members are going to family court and hospital visits. We do this for an estimated 45,000 and growing Nepali-speaking community in New York City who come from Nepal, Bhutan, India, Burma and Tibet.

Domestic worker organizing is a pillar of our community. Many of our members are nannies and home care attendants all across the city. Passing bill no. 1084 and establishing a Division of Paid Care will have an important impact on them. Over the years we have heard many painful stories about the terrible conditions of domestic work, including: wage theft, being denied rest & proper meals, unsafe work environments, and extreme isolation. Some workers put up with conditions like these for years. When I started my life in New York City I also worked as domestic worker. I experienced discrimination and dehumanization.

Organizing our community to get the New York State Domestic Worker Bill of Rights passed in 2010 allowed me to reclaim my dignity. Since the bill passed we have seen conditions improve for the workers who have been in the worst situations. We have used the bill to coach workers in negotiating with employers, and also supported workers to pursue wage theft cases. Creating a city-level Division of Paid Care will help us continue to make sure workers are treated with dignity and respect, and to raise the standards in this industry.

We would like to see the Division partner with worker centers and community-based organizations like Adhikaar and the other members of the New York Domestic Workers Coalition. We understand this industry very well, and have expertise in working with hard to reach immigrant communities. We can provide services or act as a source of support to the Division.

For our community, employment agency fraud AND labor trafficking are also important issues we have been trying to address. We were part of the Justice for Job Seekers campaign led by NY New Immigrant Community Empowerment (NY NICE) and are also part of the National Domestic Workers Alliance's Beyond Survival Anti-trafficking campaign. We would recommend these are both issues we hope the Division will investigate and engage with.

Sincerely,

Narbada Chhetri
Director of Organizing & Advocacy, Adhikaar
Resident of Woodside, Queens

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Ron Bruno, Social Worker & NORC Director, in Support of Int. No. 1084

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Ron Bruno and I am the Executive Director of Morningside Retirement and Health Services, Inc. (MRHS). In 1995 we became one of the first Naturally Occurring Retirement Community (NORC) programs designated in New York State. NORCs are such a great model for aging in place, in community. Each NORC program is customized for the particular community it's in and boasts low-maintenance with pretty good outcomes. We keep seniors out of emergency rooms and nursing homes, and save public dollars. We would not be able to meet our mission if our clients did not have good home care. Thus being involved with care workers and treating them as a professional workforce is also an important part of our work.

I have worked with MHRS for the past 20 years. Prior to this I worked in a nursing home as a social worker. As a social worker, I first came into this profession because of a desire to stand up for people who needed advocacy and a voice. A lot of people don't always see seniors falling into this category until experiencing a nursing home, where seniors are vulnerable and unable to speak up for themselves. In the nursing home I saw a lot of neglect. I also saw where there could be opportunity to help seniors stay at home longer with the right method of care and community supports. Many of those I saw coming into the nursing home had fallen for example, which may have led to a hip fracture. Next thing you know, they were in the nursing home.

Our goal is to help older adults remain living in their own homes as long as they want to. Research shows people want to age in place, and we know assistance and care at home will be needed. A paid direct-care worker is a key component in this larger equation. We have had some success stories where seniors who are pretty isolated in their homes, get on our radar, and after hiring a care worker are able to participate in our activities. The senior feels more presentable because they're getting help with their hygiene and grooming. They have more energy because they're eating better, and socializing with neighbors again. We see these seniors at our reading group, exercise classes, and movie screenings. And this can play out over years. Often there is discomfort with hiring first, but once they get over it we see gradual, and yet incredible improvement with depression lifting, socialization increasing, and the senior coming to life.

At MRHS we see a whole range of care arrangements amongst our clients. Some have 24-hour care, others have 2 shifts of 12-hour care, and those with less hours and lower level of direct support needed. There is also a whole range of professional care workers who come from all over, some from various agencies and others who work independently. Customized Care is an example of an agency that we feel confident in working with. They are a small operation, their director regularly comes on site to make sure things are working well, and their home health aides have given good feedback as well. There are also care workers who work independently who I have known for over 15 years. There's a strong relationship in place in which they will come to the center to find job openings, and we in turn will reach out when there's a need. But not all agencies are like Customized Care and many care workers who work independently need more supports as professionals. Passing bill no. 1084 and establishing a Division of Paid Care will be beneficial to this workforce, and thus beneficial to the NORCs.

A particular topic that was not addressed in the bill is that of training, agencies responsibilities for making sure workers are prepared for special conditions that clients may have, and also workers ability to access these trainings. Working with clients who have Alzheimer's and dementia specifically comes to mind. We know those with dementia can live more comfortably in their own homes. They will be less disoriented, be able to keep their pets, and be visited by people in the neighborhood they know. Again the care worker is the key and has the most impact in ensuring the senior has what they need. But when they are not trained in this specific condition, it can be very hard and a lot to manage on their own. It's not fair for the care worker to be put in that environment without that training for both the client and worker.

Agencies should be required to provide training, both basic and also for specialized care they assign workers to. And those workers who do not work through an agency should also have access to training. Basic training could encompass working with older adults, modulating your speech and giving clients time to process, basic health care skills, and more. For someone who wants to learn special care for Alzheimer's they can be trained about the condition, communication techniques, how to fill a day, and non-verbal tools out there that can enrich that relationship- such as music and art. Providing training to care workers denotes respect for the profession, as it signals that what they're doing is very important and does require skills that not everyone has. Supporting care workers to have a healthy sense of self-esteem and pride in the work improves the quality of care they can provide and also allows them to grow themselves. Nurses and social workers work with care workers daily, but the relationship can be very unequal. It is often assumed the former has all the skills and care worker just babysits. Providing training and support to care workers is also key to them working more fruitfully with the team.

Sincerely,

Ron Bruno
Executive Director, Morningside Retirement and Health Services, Inc.

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Barbara Bruce, Nanny & Family Caregiver, in Support of Int. No. 1084 & 1081

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Lisia James and I have worked as a home care worker for the last 13 years, since coming to this country. I am writing in support of Int. No. 1084, a bill to create a Division of Paid Care in New York City.

My name is Barbara Bruce and I am a professional nanny in Brooklyn. I am also a mother to a severely autistic son. I consider myself both a paid care worker and a family caregiver. I am excited about both Int. No. 1084 & 1081 because they address and support these two parts of my life.

I have been a domestic worker for over 18 years, since I migrated to the U.S. from the beautiful island of Grenada. When I started in the profession I worked in private pay home care and took care of an elderly man, 82 years old at that time, who was a lifelong New Yorker and also Air Force veteran. I would give him his medication, prepare his meals, and read to him to pass the time. Though he was blind, he had the most amazing memory. He knew exactly which books he wanted me to read, and on which page to start reading. In turn he also told me many stories about his life as a young man growing up. I really valued and enjoyed my time working with him.

For most of the past two decades I have worked as a professional nanny, taking care of children and teaching them as much as I possibly can. I show toddlers how to have a great time and be safe in parks and playgrounds. I help them transition into socializing with other children. I know I have played an important role in shaping the first years of each and every child's life that I have worked with.

I know my worth and I speak up for what I think is fair, and I ask my employers to take my experience into account. But I have seen other domestic workers put up with challenging situations and poor standards. Their job responsibilities grow endlessly, their work hours increase, but their pay remain the same. Some workers might know where to go when they have issues but most don't. And for undocumented workers, even knowing your rights does not make it easy to speak up. There is fear about being fired and being unable to find another job. Peers have recounted employers saying, "If you can't do it, I can find someone who can do twice as much for that amount." Regardless of it employers know that worker is undocumented or not, they are leveraging fear. Being undocumented and the fear of retaliation and unemployment reinforces domestic workers having their rights violated repeatedly. Establishing a Division of Paid Care will be a way to address some of this fear by educating workers and employers about their rights and responsibilities, and making it a city standard to respect this workforce.

At the end of the workday when I come home I have to take care of my son Michael, who is now 19. I give him a shower and prepare his dinner. It's like starting the day all over again. Before he goes to bed, I want to read to him but when I get to the first sentence I am so tired. After Michael is asleep, I still have to get ready for the next day which includes making sure I have enough prepared for all our meals the next day. This has been my life since Michael was 2 when his dad and I split up and Michael became my sole responsibility. While over the years I have learned about different types of subsidized assistance I could get for Michael & myself, I have to admit that I haven't taken advantage of a lot of things out there. The coordination it takes, paperwork, and appointments feels like a whole other job I don't have the capacity for. Over the years I have worked between 40, 45, and 50 hour weeks. I have to work a full-time job because I have to cover both Michael and my own expenses. I do wish I had more time and support as a family caregiver. I see bill no. 1081 being an important start.

Sincerely,

Barbara Bruce
Nanny employed in Brooklyn
Resident of East Flatbush, Brooklyn

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Sandra Hamilton, Nanny, in Support of Int. No. 1084

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Sandra Hamilton and I am a nanny. Being a nanny sometimes can be difficult if you don't know your rights. We are not always given the credit we deserve. Speaking on my behalf, I had worked with a family for three years, my hours were 12 a day, five days a week, and I was not being paid correctly. I found out a couple days before I lost my job that I was not being paid the amount I was supposed to be paid.

I have known about the National Domestic Workers Alliance for four years now and reaching out to them was very helpful for me. Now if I don't understand something I can always call and get the help I need, which is very helpful for me and others. I hope that the new Division of Paid Care will make sure the kind of support I got from National Domestic Workers Alliance is available to all nannies.

Thank you,

Sandra Hamilton
Paid Care Worker (Nanny)
Resident of Brooklyn (zip code 11236)

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Lisia James, Homecare Worker, in Support of Int. No. 1084

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Lisia James and I have worked as a home care worker for the last 13 years, since coming to this country. I am writing in support of Int. No. 1084, a bill to create a Division of Paid Care in New York City.

I care for two elderly women in my job as a home health aide, where I work 14 hours a day, 7 days a week, for just $600 per week. I live in my employers' home and nearly every day of the last 2 ½ years I have had to sleep on the couch in their living room. My back hurts me. I nearly lost my apartment last year because my wages are so little. I hardly see my family and when I do want a day's rest from work, I am required to find a replacement worker and *pay her from my own wages.* My employers think it's slavery days and the fact is my story is not unusual. Every job I've worked in this industry for the last 13 years, save for one or two good employers, is what I call the bottom of the barrel—worse conditions than anything I experienced in Trinidad.

I am telling my story because New York City must put more resources toward making caregiving work a career that people like me can survive on. I am a strong person but I am not in a place just yet where I can take legal action against my employers. But through organizations like the National Domestic Workers Alliance, I know now what my rights are and where to go once I am ready to take action. If the Division of Paid Care is going to improve the industry it must partner with worker rights organizations that are connected to the community to reach more homecare workers, provide trainings and benefits, and help them through the process of taking legal action.

Sincerely,

Lisia James
Paid Care Worker (Home Health Aide)
Resident of East New York (zip code 11207)

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Marlene Champion, Paid Care Worker, in Support of Int. Nos. 1084 & 1081

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Marlene Champion and I have provided care to seniors and children since I was 19 in Barbados. I began by caring for my aging grandmother and working for a family with 3 kids. In 1990 I migrated to the U.S. and began to work as a caregiver for in New York City and for a short while in Westchester. In 1997 I began working as a nanny, and since then have alternated between working with seniors and children and balancing the two at the same time for different families.

I was also part of the organizing efforts to pass the New York Domestic Worker Bill of Rights. The bill was an incredible victory and it's important we continue to build upon it to further support this workforce and improve this industry. I know there are domestic workers who keep their work problems to themselves. They would prefer to speak with someone who can provide professional help. Until they speak with someone often times these workers may not fully know the extent of their rights or what remedies are available. If passed, bill no. 1084 and the Division of Paid Care it would establish would be very impactful in giving domestic workers a place to go, a resource that continues to exist as time passes. I believe it is important that there's a relationship between this office and the NYS Department of Labor to make sure that workers are able to full enforce their rights.

I am also an informal family caregiver along with my daughter Stephanie for my grandson Damien. Damien had a vehicle accident this past year and suffered spinal cord injuries that has taken away his ability to walk. He has been through multiple surgeries, and, immediately after the accident, he was not able to use his hands and feed himself. Although he's currently in a facility, I visit almost daily to provide some care and company. It has been 7 months since his accident. It has put me in the position where I don't have time to do anything for myself. I have to look out for him and also for the family I work for as a nanny.

I am turning 71 this year, and I can't even think about slowing down. I was planning to stop work and retire at the end of 2017, but due to what happened to Damien I have to think things over. I have started looking for housing for when Damien leaves the facility and moves back in with me. I currently live on the 4th floor of a Crown Heights apartment without an elevator. We will need to find a home that can be made physically accessible for Damien. I also have to consider the finances we will need to support Damien as he gets back on his feet. All of this makes it challenging for me to save for my retirement and the care I will need as I age. Bill no. 1081 is also very important, and family caregivers like myself who suddenly find themselves in this position need support that help us provide the best care possible for our loved ones and also for ourselves.

Sincerely,

Marlene Champion
Resident of Crown Heights, Brooklyn (zip code 11213)

FOR THE RECORD

April 11, 2016

New York City Council

Testimony of Santi Lama, Nanny, in Support of Int. No. 1084

Dear Members of the Committee on Aging and Committee on Civil Service & Labor,

My name is Santi Lama, I come from Nepal, and I work as a nanny in Brooklyn. When my former employer refused to pay me for my last week of work, as punishment because I know longer wanted to take their disrespect, I thought there was nothing I could do. But my roommate told me to go to Adhikaar, that they could help me there. I am currently pursuing wage theft claims for unpaid overtime against my former employer. If it weren't for Adhikaar, I wouldn't have known this was my right.

Domestic workers feel like they have to accept whatever employers are willing to give them and in today's reality they are right. If we want to be hired or keep a job, then we have to accept industry norms because employers know they can find someone else who doesn't know their rights or who will work for less. There needs to be a collective change across the industry because individual workers cannot do this alone. I hope this new division will make changes on a bigger scale that doesn't solely rely on individual workers enforcing their rights.

The new agency should also make sure referral agencies are not sending nannies to jobs that violate their rights. I found the previous job through a referral agency that is used by many Nepali nannies. Referral agencies are a way that many nannies in my community find work and it should be part of the new division's job to make sure agencies are only placing nannies in good jobs.

Sincerely,

Santi Lama
Paid Care Worker (Nanny)
Resident of Elmhurst, Queens (zip code 11373)

AARP Real Possibilities in

New York City

Testimony of
Chris Widelo, Associate State Director

New York City Council
Committee on Aging
Committee on Civil Service and Labor

Int. 1081
Int. 1084
April 11, 2016

City Hall
New York, New York

Contact: Chris Widelo (212) 407-3737 | cwidelo@aarp.org

INTRODUCTION

Good afternoon Chairwoman Chin, Chairman Miller and members of the Aging and Civil Service and Labor Committees. My name is Chris Widelo and I am AARP's Associate State Director for New York City. On behalf of our 800,000 members age 50 and older in New York City, I want to thank you for the opportunity to testify on two important bills before your committees today.

Int. 1081 – Addressing the Needs of Informal Family Caregivers

Family caregivers provide an invaluable resource in caring for their loved ones at home – many on call 24 hours a day, seven days a week. This labor of love is worth more than $30 billion in unpaid care each year statewide. Thanks to family caregivers' commitment, millions of older people are able to live at home rather than in costly institutions, like nursing homes. While family caregivers wouldn't have it any other way, it's a big job – and you never truly understand what a caregiver goes through until you find yourself in that position.

I have personally had the opportunity to hear directly from informal family caregivers about the many services they provide and the frustration they feel when they encounter "red tape" or do not have access to the resources they need to successfully do their job. It is heartbreaking. What is even more heartbreaking is that many of these caregivers are unable to care for themselves or take the time to recharge so they can continue to provide this valuable service to a loved one. I invite you to visit AARP's IHeartCaregivers.com website to read real stories left by unpaid family caregivers here in NY.

AARP supports Int. 1081because we believe that the better we can understand the types of services our family caregivers provide and their unmet needs, the better our City can meet those needs and prepare for the future when even more aging New Yorkers will rely on the care provided by a family member or loved one.

AARP recommends amending the proposal and replace “informal caregivers” with “informal family caregivers” or “unpaid family caregivers” to recognize that this care is in fact unpaid and most often performed by a family member.

Int. 1084 – Establishment of a Division of Paid Care

When care at home is not being performed by an unpaid family member, it is often being performed by a paid caregiver such as a homecare worker. Homecare workers are an important part of the caregiving continuum and provide important services that allow New Yorkers to remain in their home and successfully age in place.

AARP agrees that it is important to understand the needs of the homecare worker and the person receiving care given the often complex and evolving nature of the work involved. As the backbone of paid in-home care, is important that our homecare workers have access to information, training and other services so they can do their job effectively. It is our belief that this will result in a better experience and quality of care for those receiving homecare services.

AARP supports Int. 1084.

CONCLUSION

Chairwoman Chin, Chairman Miller and members of the Aging and Civil Service and Labor Committees, thank you for the opportunity to testify on these important proposals and we hope that they are both passed favorably out of their respective committees.

NICE
NEW IMMIGRANT COMMUNITY EMPOWERMENT

FOR THE RECORD

Testimony of Maritza Ortiz, Organizer
New Immigrant Community Empowerment (NICE)

In Support of Int. No. 1084

Presented Before the New York City Council Committee on Aging and Committee on Civil Service and Labor

April 11, 2016 at 1:00 pm

Good afternoon, my name is Maritza Ortiz. I worked for many years a housecleaner on Long Island and am now the Organizer of Women Workers at NICE (New Immigrant Community Empowerment), a community organization in Jackson Heights, Queens.

Most nannies and domestic workers that I organize are live-in workers, they are extremely isolated, and they know very little of their rights. Due to the difficulty of reaching this workforce, it is essential that the new Division of Paid Care partners with community organizations that have ties with the communities these workers come from.

NICE also urges the City Council to include in the law an explicit commitment to take into account the specific needs of immigrant and undocumented workers. We hope the Division will form a strong partnership with the Mayor's Office of Immigrant Affairs.

Finally, as one of the leaders of the Justice for Jobseekers campaign, which has fought against consumer fraud by employment and referral agencies, NICE recommends that the City Council include these referral agencies as another type of entity to be researched and regulated under this law. Many immigrant workers in the paid care industry find work through these referral agencies. Although they are not technically employers under the law, these agencies do have responsibilities to these workers and they are a point of contact where the Division of Paid Care can reach more workers.

Thank you for the opportunity to testify on behalf of Intro. No. 1084.

My name is Sylvia Vogelman, and I'm here to today to offer testimony in support of the creation of the Division of Paid Care (Intro 1084). I want to enthusiastically applaud the efforts and foresight of the Speaker and her staff in taking this step towards acknowledging the importance of care and caregiving.

I am a member of a grassroots citywide organization called Jews for Racial and Economic Justice. JFREJ is a local affiliate of Hand in Hand: The Domestic Employers Network and a field anchor of the Caring Across Generations campaign. I am also a member of a synagogue on the Upper West Side called B'nai Jeshurun. Wearing all these hats, I've been involved in extensive community organizing and advocacy efforts related to aging in place and caregiving for the last 4 years. For over 20 years I've been a kitchen volunteer at GLWD and have previously served as it's board Co-Chair for 10 years. I am presently on the Chairmans Council. I am the daughter of immigrants who survived the Holocaust and were fortunate enough to come to America. My parents were working class – my father was a window cleaner and my mother worked in a factory.

I am a proud elder boom activist. We call ourselves the Caring Majority because we are committed to building a strong and sustainable caring economy that works for all of us--seniors, family caregivers, people with disabilities, direct care workers, and domestic workers. We are grounded in the conviction that caring homes and just workplaces--quality care and quality jobs--go hand in hand.

I know that a strong and professionalized home care workforce--with robust training and career ladder opportunities--will be key if my neighbors and I are to continue living independently in our communities as we age. I want to live in a city in which all care workers earn living wages and receive real benefits and respect on the job. This isn't only about recognizing the inherent value of caregiving. It's also about recognizing my inherent value as an older adult.

The Division of Paid Care is a critical first step in preparing our city to face the elder boom. This office can play a powerful role in increasing clarity, professionalism, and compliance in this fast-growing sector. To that end, I'd strongly recommend the explicit inclusion of collaboration with community organizations like ours in the office's programs. This partnership will ensure that the office can reach all the care workers in the city; it's also crucial for reaching communities of employers like mine. Domestic employer outreach, education, and compliance with labor laws has been an area that has been deeply explored and undertaken at JFREJ, Hand in Hand, and my synagogue. We hope that the new Division of Paid Care will design a partnership with our organizations and contract us to do some of this work, thereby reaching specialized populations with whom we have experience.

As Linta and Rachel have mentioned, our My Home is Someone's Workplace program is a powerful and effective method for educating employers about their rights and responsibilities, building capacity for clear supervision practices, and establishing open and trusting communication from the get-go. In 2014, in partnership with JFREJ, NDWA, and Hand in Hand, we launched a first-of-its-kind training program eldercare workers, with a parallel track for seniors and their loved ones who wanted to gain a variety of soft and hard skills for effectively managing care for themselves or a loved one. The training for employers included:

- Best practices for hiring and supervising
- Legal rights and responsibilities of employers
- Clear and open communication with a paid caregiver
- Conflict resolution
- Role of the family in care management
- Planning, budgeting, and decision making

With limited resources, we currently hold monthly My Home is Someone's Workplace workshops in a handful of Naturally Occurring Retirement Communities and senior centers around the city. We would be thrilled to partner with the new Division of Paid Care to bring this critical program to scale.

I'd also like to echo the need for a multi-stakeholder advisory board for the Division of Paid Care. In addition to direct care workers, home care agencies, and other service providers, it should include people like me: individual private pay domestic employers who are trying to make it work, counting on domestic workers to maintain our independence. As we've learned through our work, the interests of individual families and the workers they employ are more aligned than you might realize. We share a mutual interest in greater recognition for care work and caregiving, leading to more support for this critical workforce and more support for individuals and families to access and afford the care that we need.

On the subject of access to care, while we know that there are significant limits on what the city can do in the area of care affordability, we hope that this new office will partner with our organizations through research and data-collection to send a strong and urgent message to your colleagues in Albany. Long-term care and childcare affordability need to be taken seriously. I'd also like to say that we strongly support Intro 1081, which would require DFTA to conduct a survey of informal caregivers (family members providing unpaid care to relatives) and carry out a plan to address the needs of this population in the city. Support for family caregivers is a critical piece of the puzzle in our movement of the Caring Majority.

In closing, I'd like to invite the Council Members present today to join the Movement of the Caring Majority by sharing your own experiences of care and caregiving. **Share Your Care** is a project by Caring Across Generations where elected officials and public figures tell their own caregiving story, to show that caregiving is an issue that touches us all. Telling our caregiving stories today will make it possible to build a movement to change caregiving policy tomorrow. You can join the conversation by coming and saying hello to me after today's hearing, or by e-mailing shareyourcare@caringacross.org.

Thank you.

Testimony of Carol Rodat
New York Policy Director, PHI

Before the

Joint Hearing of the Committees on Civil Service and Labor, Aging and Finance
of the New York City Council

on

Int. 1081, 1084 and Res. 993

April 11, 2016

PHI thanks the committees for the invitation to testify at this hearing. PHI (Paraprofessional Healthcare Institute), is a national not-for-profit organization headquartered in the Bronx that works to transform eldercare and disability services. We foster dignity, respect and independence for all who receive care, and all who provide it. We are the nation's leading authority on the direct care workforce and promote quality jobs as the foundation for quality care. PHI has been one of the organizations that has advocated on behalf of better pay and benefits for the direct care workforce, as well as the new home care rule which extends the minimum wage and overtime protections of the Fair Labor Standards Act to home care workers.

My name is Carol Rodat, and I am the New York Policy Director for PHI. In that role, I advocate for the policies and practices that will improve the quality of the jobs of the many titled direct care workers – home care aides, personal care aides, personal assistants, certified nursing assistants and direct support professionals. I have been directly involved in the development of laws, regulations and policies that support the home care workforce, including the Wage Parity law, the Fair Labor Standards Act, and the Sleep-In cases. In my role, I also seek adequate reimbursement rates to cover the costs associated with direct labor.

In addition, I currently serve on the Institute of Medicine's (IOM) Committee on Family Caregiving of Older Adults. That committee is charged with assessing the prevalence of family caregiving, examining the available evidence on the effectiveness of programs and supports for caregivers, and recommending policies to address the needs of family caregivers in order to minimize the barriers they encounter in trying to meet the needs of older adults. The IOM's report with recommendations will be released later this year.

I would like to first address proposed legislation that would authorize a survey of informal caregivers, public and private service providers and service recipients in order to assess existing services and needs (Int. No. 1081). The majority of the hands-on care in this country and state is provided by informal caregivers who are often referred to as "family caregivers." However, in many instances, there is nothing "informal" about the care they are being asked to provide. Today's unpaid caregivers who may have family kinship to the care recipient or not, are asked to provide a range of tasks, from arranging medical appointments, assistance with personal care or household chores to assistance with feeding tubes and catheters. Limited hospital stays and quicker discharges now include the implicit assumption that families will be available to assist with the transition from hospital to home.

At the end of this month, the New York State Caregiver Advise, Record and Enable Act (CARE) will go into effect, requiring hospitals to offer instruction to designated family caregivers prior to discharge. The law also ensures that the family caregiver's name can be included in medical records and that they will informed of an impending discharge. Instruction and demonstrations of health-related tasks will be offered when the family member is expected to provide certain supports such as administering medications or dressing wounds. While this legislation targets a very important gap in the delivery system, it does not address the ongoing long-term needs that families face when a loved one has a chronic or debilitating condition such as Alzheimer's, Multiple Sclerosis, cancer or ALS. Moreover, as we age we encounter functional limitations without the onset of serious chronic disease that require long-term assistance and support -- and the burden is increasingly falling to families and friends.

Before I address the specifics of the legislation (Int. No. 1081), it is important to underscore the reality of today's demographics as the data are reflective of the importance of the proposals under consideration. While the country's older population is growing – with an expectation that one in five U.S. residents will be 65 or older by 2030, the pool of family caregivers is shrinking – as is the pool of potential paid caregivers. Families are having fewer children, older adults are likely to have never married or divorced and children often live far away. In the past, the women in the family could be relied upon to be available. In fact, the typical caregiver is still female, but more wives, daughters and daughters-in-law now are working and therefore have limited availability, particularly if they have other responsibilities.

The demographics create an imperative for unpaid family as well as paid caregivers. It becomes critical that society understand that caregiving will become a shared responsibility as each of us is likely to need to care for someone in the future if we have not already done so.

Despite the fact that we are an aging society, one with growing health care needs, our focus, particularly here in New York, is often on the formal health care system rather than the aging system's supports and services that have been developed over several decades. In fact, as our health care system continues through the transformation that began with Medicaid Redesign, individual providers of health services often remain disconnected from the other services that families need when they are called upon to provide care for a loved one. The Older Americans Act funds the first and only program specifically for family caregivers – the National Family Caregiver Support Program (NFCSP), which addresses the needs of caregivers for older individuals as well as grandparents and other relatives raising grandchildren. New York has provided resources for families caring for those with Alzheimer's and dementia, but there are other conditions that lead to long-term caregiving needs. Moreover, when caregivers step into these roles, it is important that their needs be assessed and addressed. Otherwise, their ability to continue to support their loved one is jeopardized along with their health.

In summary, the responsibility for caregiving will continue to be borne by families and others, making it essential that we as a society better understand what services and approaches are needed, whether or not they have been proven to be successful, whether we have sufficient numbers of services and supports, and whether or not they are accessible and delivered in a manner that is culturally competent. While the City's services are an important factor in support for family caregivers, we should be mindful of the fact that the programs and services provided by the City and State can be supplemented by workplace policies and practices that allow flexibility and discourage discrimination.

PHI believes an assessment of the needs, supports and services available to caregivers in New York City is needed, and wishes to register several recommendations and concerns which have been forwarded to counsel and are attached to this testimony:

- The scope of the study is so broad as to prohibit careful analysis and recommendations;
- More than three months is needed to design, test, administer and analyze a survey of this scope;
- The design, administration and analysis of the survey must be fully funded in order to obtain the information desired;
- Survey design would be facilitated by involvement of individuals in the field with experience in the development and administration of surveys of this type;
- Design of the survey should take into consideration the fact that many family caregivers, particularly those from diverse ethnic backgrounds, do not "identify" as such but with the right questions, reveal an extensive amount of support is being provided by them;
- Data should also be collected as to how much paid care informal caregivers are utilizing, and whether or not it is satisfactory and of sufficient amount; and,
- Consideration should be given to how current services might be provided in concert with the health care delivery system

I would now like to turn my attention to legislation that would establish a Division of Paid Care within the Office of Labor Standards. PHI was consulted as to various strategies and programs that could support the direct care workforce. We strongly support this proposal and believe recent changes in labor and public law have created a need for an independent advocate on behalf of the workers. The home care workforce—home health and personal care aides caring for elders and people living with disabilities-- is the second largest in the City of New York, numbering over 288,000--only retail sales workers outnumber these caregivers. They contribute to the City's economy and many are the single heads of households with dependents who rely on their income as well.

New laws, administrative rules and court decisions have improved the wages and benefits of the direct care workforce while creating a complex set of requirements that combine to make understanding accurate calculation of wages earned very difficult. The most important changes are the newly passed state minimum wage, the Wage Parity Law, and the Fair Labor Standards Act. Paid Sick Leave and the New York State Domestic Workers Bill of Rights also provide important time off benefits and access to leave. The newly passed Family Medical Leave Act will also provide extended time off without loss of income when finally implemented in 2018.

The best means of conveying the complexity of the situation and the rationale for additional information and support for workers is to provide an example of overtime pay calculation for an aide working in one of the New York City boroughs:

The aide's base rate is $10.00 an hour as required by the Wage Parity Law. Now that she is covered by the Fair Labor Standards Act, she receives the state's minimum wage of $9.00 for travel time between clients. She works 40 hours taking care of clients in a workweek and has 5 hours of travel time during the week. Her calculated regular rate of pay is $445.00. However, when divided by the 45 hours of work and travel combined, her average rate becomes $9.89 which is the rate she will be paid for the 5 hours of overtime, bringing her total to $469.73.

On January 1, 2017, when the first step in the increase in the state minimum wage takes place, bringing the minimum wage in New York City to $11.00 for employers with at least 11 employees, travel time will be paid at the same rate as regular time worked which will simplify the computation somewhat. However, consider the fact that many aides work cases in the New York City boroughs as well as Westchester or Long Island where the minimum wage rates will be different as these workers cross county lines.

There are numerous situations that impact home care worker wages as a result of state and federal requirements. For example, aides must attend 6 or 12 hours of in-services[1] annually and must have physicals and competency tests. Travel to these required events must be paid, as must travel to disciplinary meetings. "Wait time" and "On Call" time are compensable. And should the aide work the night shift for a client who needs round-the-clock care, she is entitled to be paid for every hour if she does not receive at least 5 hours of uninterrupted sleep.

The creation of the Office of Labor Standards was a very important step in advocacy for all workers in New York City. A Division of Paid Care can focus the attention on hourly workers in direct care and help workers and their employers understand and receive the wages and benefits they have earned.

Finally, PHI wishes to thank the Council sponsors of the resolution that calls for an expansion of the child care tax credit. In June of 2014, PHI in concert with Wider Opportunities for Women, published a study of the impact of Wage Parity on eligibility for public benefits such as the Child Care Tax Credit, the Earned Income Tax Credit, Housing Choice Vouchers, Supplemental Nutrition Assistance, WIC and health insurance. Access to public benefits contributes to a modicum of financial security and is very important to low wage workers. In the case of home care workers, reliance on benefits is essential in many cases as home care hours are often irregular as clients are hospitalized or change managed care plans. In fact, PHI has learned from several large employers and consumer advocates that most aides are working on average 30 hours and many now work for two different employers in order to piece together sufficient income.

PHI appreciates the leadership and consideration that has been shown by the New York City Council for family caregivers and direct care workers, two very important and large groups of people who take care of others in need. Your recognition of their value, as evidenced by the proposed legislation, makes this City a model for others and will go a long way towards helping its citizens age safely in their communities.

---

[1] Personal care aides, often referred to as Home Attendants in New York City, are required to complete 6 hours of in-service training on an annual basis, and Home Health Aides are required to complete 12 hours of in-service training on an annual basis..

PHI Quality Care THROUGH Quality Jobs

PHI Comments on the Proposed Comprehensive Plan to Address the Needs of Informal Caregivers (Int. 1081-2016)

The nation's leading authority on the direct-care workforce, PHI has helped organizations, advocates, and policymakers across the U.S. to improve the quality of long term services and supports (LTSS). Since its establishment in 1991, PHI has worked to improve LTSS through workforce and curriculum development, coaching and consulting services, and policy and research efforts.

We applaud the City Council's goal of supporting informal and family caregivers. Informal caregivers are valuable members of the caregiving team, who make it possible for countless individuals to remain in the community rather than being institutionalized. PHI's work with paid caregivers who serve the young, the aged, and those who are living with disabilities has given us enormous insight into informal caregivers' experiences. PHI's New York Policy Director, Carol Rodat, is currently serving on an Institute of Medicine (IOM) committee that has been empaneled to make recommendations on Family Caregiving for Older Adults. The IOM report is scheduled to be released this summer, and the work will catalog interventions on behalf of caregivers that have been shown to have efficacy.

The comments that follow aim to ensure that the informal caregiver survey is developed and administered in the most effective manner, produces information that is clear, useful and directional, and leads to recommendations that truly improve informal caregiver supports and services.

Overarching Comments

As previously mentioned, PHI believes the intent of the proposal is laudable. However, the development and administration of the survey is of such scope that the analysis and creation of recommendations will be difficult. . In order for this to be successfully accomplished, PHI believes the legislation must be accompanied by a narrower focus and funding as well as input from experts in the field.

While the New York City Department for the Aging (DFTA) has experience in working with the aging population, it does not necessarily have expertise in the design of surveys for caregivers. PHI strongly recommends that the design of the survey be funded first and that DFTA work with researchers with experience in developing and administering surveys of this nature. This will help to ensure that the survey will successfully capture the information outlined in the legislation. Depending on how the survey would be executed, it is possible that the populations such as those serving the aged and those caring for grandchildren should be surveyed differently and separately.

Informal caregivers interact with the formal health delivery system, and the extent to which that system is connected to the City's support network needs to be assessed. Consideration should be given to identifying the specific ways in which the aging network is currently supporting family and informal caregivers, and how those services could be or should be expanded – or new services could be delivered – through opportunities provided by the health care delivery system.

Additional Comments

§21-206(a) Definition of Informal Caregiver

The definition of informal caregiver includes four groups that provide different types of care and access different systems to provide that care. Caregivers in the first two groups (i.e., providing care to a person who is 60 years of age or older and providing care to a person with Alzheimer's disease or a related disorder) tend to access supports through the aging system. However, the third group – relatives who are 55 and older providing care to children under the age of 18 – have vastly different caregiving needs that are typically not necessarily met through the aging system. Similarly, adults providing unpaid support to individuals with disabilities tend to utilize different services and go through the disability services system to meet their needs. PHI recommends that the scope of the survey be targeted, or that three separate surveys be conducted with experts in each field participating in the development and administration of each.

§21-206(b) Timeframe

The scope of this legislation would require a much longer timeframe to design, test, administer, and analyze. Based on feedback from organizations with expertise in this area, PHI would recommend a timeframe of at least six months for the design and a year to complete the survey. We would also envision active involvement from various agencies and constituencies in order to identify the best means of achieving a valid sample.

§21-206(b)(5) Satisfaction Data

Recipient satisfaction with existing programs and services is extremely important. However, since the focus of this survey is on the informal caregiver, PHI recommends also collecting data on caregiver satisfaction with existing programs and services.

§21-206(c) Publication of Findings

PHI applauds the requirement to consult with appropriate agencies, informal caregivers, and academic experts in the development of the comprehensive plan. However, as with the development and administration of the survey, PHI recommends that a longer timeframe be allowed. PHI recommends that the survey administrator be given at least 6 months after the completion of survey administration to analyze results, meet with stakeholders, and develop a comprehensive plan.

Additionally, PHI recommends that survey results be compared to national data sets, such as the National Study of Caregiving (NSOC) and the National Health and Aging Trends Study (NHATS). This will allow NYC to gauge where it stands in comparison to national results.

§21-206(c)(2) Data

It will be extremely useful to have data on the number of informal caregivers and the hours of care they provide when determining goals. PHI recommends the inclusion of additional data on who the informal caregivers are providing care for, as well as the utilization of paid care in conjunction with unpaid care. If informal caregivers are utilizing paid care, PHI recommends collecting data on what types of paid care, how many hours, how they are paid for, and if caregivers feel the amount of paid assistance they receive is sufficient. This information will further assist the city in determining the amount and scope of needed caregiver supports and services.

§21-206(c)(3) Recommendations

PHI is supportive of the legislation's directive to create measurable recommendations which are regularly reported and updated. We recommend that these recommendations should be prioritized when developed and submitted. This will help to ensure that the most urgent needs are addressed more quickly.

<u>Concluding Thoughts</u>

PHI greatly appreciates the opportunity to provide comments on this legislation. With the aging of our population, it is important to have an accurate picture of the needs of informal caregivers and to determine how they can best be supported. These supports improve the quality of life for both caregivers and those they provide care to. PHI hopes that our comments are helpful in developing a highly effective informal caregiver plan.

PHI Quality Care
THROUGH
Quality Jobs

A Public Advocate for New York's Home Care Workers: A New Role to Strengthen the Workforce

By Carol A. Rodat and Allison Cook

PHI Discussion Paper

Pre-publication: Do Not Copy or Distribute

PHI Medicaid Redesign WATCH
Shaping the Future of New York's Home Care Workforce

Home care aides provide essential personal care and health-related services to older New Yorkers and people living with disabilities, helping them to remain independent as long as possible. Despite the critical importance of their work, treated as "domestic workers," home care aides have historically earned low wages and had few labor protections. In recent years, as demand for home care has grown and providing these services has become a policy priority, lawmakers have reversed course, passing new laws and regulations which better safeguard home care workers from unfair treatment.

This new array of laws and regulations, though well intended, is multilayered and complex. Both workers who want to better understand their rights, and providers who want to abide by the law, find the new rules complicated and at times confusing. There is a great need for better information if the new rules are to be implemented effectively.

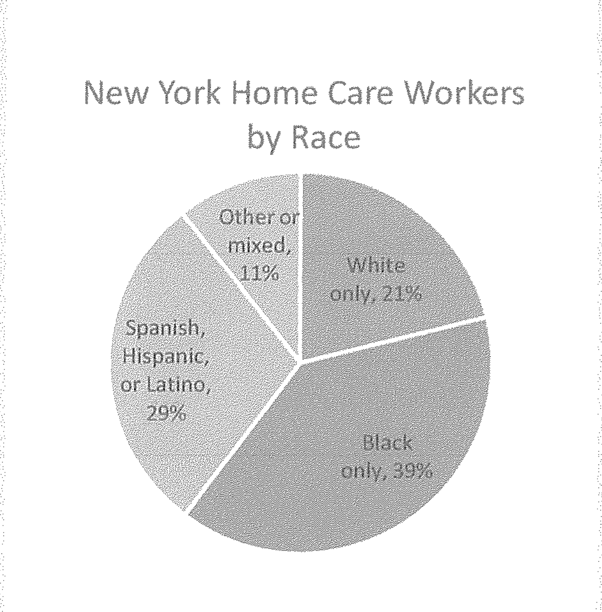
In light of these recent developments, PHI believes there is a need for a *public advocate for home care workers*, an entity or person who would function as an ombudsman, ensuring that workers and providers can navigate these rapidly changing legal requirements.

Background

The New York State home care aide workforce – which includes personal care aides (or "home attendants") and home health aides – totals over 288,000, with more than two thirds of these workers employed in New York City.[i] These workers provide daily supports to hundreds of thousands of older New Yorkers and people living with disabilities, including assisting their clients with bathing, dressing, meals, cleaning, shopping, and going to school or work.

The structure of the home care system puts home care aides – many of whom have little post-secondary education

WHO ARE HOME CARE WORKERS?



- The median age of a home care worker in NY is 48 years old.
- Two thirds of home care workers in NY are foreign-born.
- 67 percent of NY home care workers have a high school diploma or less.

Source: PHI analysis of the American Community Survey, U.S. Census Bureau (2015). 2014 ACS 5-year PUMS. Retrieved from http://www.census.gov/programs-surveys/acs/data/pums.html and for whom English is not their first language (see Did You Know box)– at a disadvantage when it comes to knowing their rights and challenging unfair treatment. Home care aides typically do not have the peer support and knowledge-sharing that comes from regularly interacting with coworkers in an office.

Labor unions provide information and support to their members, but a significant number of New York's home care workers are not unionized. This leaves employers as the sole source of work-related information for many home care aides. Despite providing required information on workplace laws and regulations, employers are not necessarily seen by employees as a neutral source of information. Workers perceive an inherent conflict of interest, particularly when they are concerned about a violation that could affect their employment or their pay and benefits.

Ultimately, state and federal government agencies, which pay for the majority of home care services through Medicare and Medicaid, are responsible for ensuring that labor laws and regulations are properly enforced. However, their capacity to do so is limited. Currently, the New York State Department of Labor (DOL) has staff limitations and investigates an issue only after a critical mass of complaints is lodged against an employer or the violation is egregious. Additionally, the New York State Department of Health (DOH), which regulates home care, shares responsibility with the state DOL for ensuring that home care aides are treated fairly by their employers. This requires a level of coordination that the departments' broad mandates and limited budgets make difficult at best.

DID YOU KNOW?

	Current Employment[1]	Entry Level Income[1]	Median Income[1]	Projected Increase (#) 2012-2022[2]	Projected Increase (%) 2012-2022[2]
Home health aide	146,550	$18920	$22,050	58,630	45.3%
Personal care aide	142,220	$20,760	$23,330	52,510	36.9%

Source: [1]NYS Department of Labor, Labor Statistics. Occupational Wages (2015 First quarter). Retrieved from: http://labor.ny.gov/stats/lsWage2.asp

[2]NYS Department of Labor, Labor Statistics, Long-Term Occupational Employment Projections (2012-2022). Retrieved from: http://labor.ny.gov/stats/lsproj.shtm

New Labor Laws Impacting New York Home Care Aides

There have been a number of recent changes to wage and labor protections for home care aides. These changes, detailed below, create a complex network of rules.

1. New York State Domestic Workers Bill of Rights **(DWBR)**: Enacted in November 2010, this law previously only applied to home care aides directly employed by their clients. Upon the reinterpretation of the Fair Labor Standards Act (see #5), this law became applicable to agency-employed home care aides as well. In addition to guaranteeing workers one day of rest each week and three additional paid days off per year, the law provides certain protections against discrimination and harassment.[ii]
2. Wage Parity: As part of its effort to redesign the state Medicaid program, the New York State Legislature passed a wage parity requirement for home care aides as a component of the 2012 budget. By establishing a wage floor, the legislation brought the compensation of home health aides in line with that of home attendants in the downstate areas of New York City, Westchester, Nassau and Suffolk counties.[iii] As of March 1, 2016, the wage parity law guarantees home care aides compensation (including wages and benefits) of $13.22 per hour in Long Island and Westchester and compensation of $14.09 per hour in NYC.[iv] The law does not apply to workers in upstate New York counties. A recent amendment to the law requires a continuation of the benefits of $4.09 for New York City and $3.22 for the surrounding counties on top of the new minimum wage (see #4).
3. Paid Sick Leave: Home care aides who work in New York City are protected by the City's Earned Sick Time Act, which went into effect in 2014. Full-time workers are guaranteed one hour of paid leave for every 30 hours of work, and this leave may be taken to care for oneself or a loved one. This law guarantees two days of sick leave, in addition to the three days of rest provided by the state Domestic Workers Bill of Rights.[v] The New York State legislature recently passed a new Paid Family Leave policy which will broaden this benefit beginning in 2018.
4. Minimum Wage: The state minimum wage increased from $8.75 to $9.00 per hour on December 31, 2015.[vi] With the recently passed New York FY17 budget, the minimum wage is scheduled to rise to $15 per hour in NYC by 2018 and in Westchester and Long Island by 2121. The rest of the state will increase to $12.50 by 2020 with a pause for review to determine the impact on the economy. As these increases go into place, the wage portion of the wage parity requirement will be $10 an hour or the new minimum wage, whichever is higher.
5. Fair Labor Standards Act (FLSA): In October 2015, home care aides across the country became eligible for labor protections under the federal Fair Labor Standards Act (FLSA). As a result, home care aides are now protected by minimum wage laws, and must be paid time-and-a-half on their base wage (instead of time-and-a-half of the minimum wage, as was previously the case in New York) for overtime above 40 hours per week. Employers are also newly responsible for paying aides for time spent traveling between clients.[vii]

In addition to these new rules and regulations, required compensation could be altered by several ongoing court cases seeking to increase compensation for aides when they provide 24-hour care.[viii]

Currently aides are compensated for 13 of the 24 hours, based upon the supposition that they receive five uninterrupted hours of sleep and three one-hour breaks for meals. The court challenges seek to ensure aides are compensated for a full 24 hours, regardless of whether they receive their uninterrupted sleep and meal time.

The Home Care Advocate Role

In this extremely complicated environment, home care workers have no centralized resource that provides support and education on the full range of applicable labor and wage rules, and neither do employers. Consequently, PHI finds need for an advocate who would be well versed in the home care labor rules and requirements. Such a person could operate at the state or city level, could be independent, or could hold a position within an existing agency or office. The role of the public advocate would include three main components:

What is an Advocate?

An advocate, also known as an ombudsman, is a person or entity that works on behalf of an individual or group of individuals to address an issue. An advocate is an objective, independent resource that can help answer questions and handle complaints. In New York, there are a number of advocates that work in an official capacity on behalf of home care and long-term care consumers, such as the Independent Consumer Advocacy Network (www.icannys.org), the Long-Term Care Ombudsman (http://www.ltcombudsman.ny.gov/), and the Medicare Beneficiary and Family Centered Care Quality Improvement Organization (http://www.livanta.com/bfccqio.html). However, most home care aides are left without this valuable resource.

Education: The largest share of the advocate's work would be to help home care workers learn about labor laws and regulations and answer their questions. As one example, the advocate could spearhead a public education campaign that might include in-depth educational sessions or the development of materials for employers and workers on rules regarding compensation and labor protections. The advocate would also be available via a toll-free phone number to answer any questions workers have about their rights.

Tracking and Reporting: The advocate could create a system for reporting complaints and making referrals to the proper enforcement agencies. An effective system would provide workers with a supportive environment in which to learn about their rights and file a complaint, if warranted. The advocate could track complaints and issue an annual report describing type and frequency. The most prevalent complaints could be reviewed to determine a course of action, such as an education campaign or a regulatory or legislative intervention.

Assistance and Support: The advocate could also help workers access state and local services for low-wage workers. For example, if a worker were in need of child care or health care, they could refer the worker to appropriate services or resources. In addition, the advocate could provide information on available training programs and their costs.[ix]

Overall, with the support of a public advocate, home care aides would be better informed and empowered to speak up on their own behalf, and existing labor laws and protections would be better enforced.

Ideas for Further Discussion

The public home care advocate role proposed in this brief is meant as a starting point for further discussion among the multiple stakeholders invested in a quality home care system for all New Yorkers. Some of the issues that deserve robust conversation and consideration include:

- **Location:** State and local offices will be needed to fully support home care aides. The newly created Office of Labor Standards in New York City could serve as an appropriate place for the advocate, as City Council Speaker Mark-Viverito proposed in her February 2016 State of the City speech[x] and through legislation supported by five other city council members.[xi] At the state level, DOL could provide a place for the work through its new Anti-Retaliation unit. Alternatively, a neutral third-party organization could be tasked with the work.
- **Skill Set:** The advocate should possess knowledge of the pertinent wage and hour laws as well as organizations and offices to which a worker could be referred. An attorney with experience as a labor lawyer would be ideal, but a person with a strong understanding of the home care system could also serve in this capacity with support from organizations that provide legal services.
- **Relationship between the State DOL and DOH:** As previously discussed, DOL and DOH are jointly responsible for protecting home care aides. These departments likely need additional resources to effectively monitor and enforce relevant labor laws. Further, regular communication across the agencies and with the advocate would need to be addressed in order to ensure that complaints and other issues were considered in a timely manner.
- **Advocate's Role in Recruitment of Home Care Aides:** An additional role for the advocate's office might be helping to grow the workforce through a public education campaign to recruit new aides into the field. The advocate might assist potential workers in understanding the training requirements and direct them toward free training programs that are connected to employment.

Conclusion

New York's home care aides have made considerable progress toward becoming a respected, professional workforce that provides highly valued services to elders and people living with disabilities. However, these workers struggle with complex new rules, laws and regulations that have come into effect over the last five years and continue to be adjudicated. Consequently, PHI proposes creating a position for a public advocate for home care workers. This position would educate, track and report complaints; refer workers to appropriate resources for challenging unfair treatment; and provide assistance on a range of matters important to home care aides. In addition, the advocate could indirectly help identify other serious issues affecting the home care field, including high worker turnover and low worker retention. The end result would be a home care system that better supports it workers and better enables them to provide quality care.

PHI works to transform eldercare and disability services. We foster dignity, respect, and independence– for all who receive care, and all who provide it. The nation's leading authority on the direct-care workforce, PHI promotes quality direct-care jobs as the foundation for quality care. In New York, PHI is affiliated with Cooperative Home Care Associates, a worker-owned home care agency, and the managed-care plan Independence Care System (ICS).

PHI Medicaid Redesign WATCH is a three-year project to record, analyze, report—and intervene to mitigate dislocation of consumers and workers—as New York fundamentally transforms its Medicaid-funded long-term services and supports. Funding for this initiative is provided by the Ira W. DeCamp Foundation, the Ford Foundation, the Altman Foundation, and the Bernard F. and Alva B. Gimbel Foundation.

References

---

[i] At: http://www.labor.state.ny.us/stats/lswage2.asp

[ii] https://labor.ny.gov/legal/domestic-workers-bill-of-rights.shtm

[iii] See http://phinational.org/research-reports/medicaid-redesign-watch-1-wage-parity-home-care-aides

[iv] New York State Department of Health. "MRT-61 Home Care Worker Wage Parity." Accessed on February 8, 2016 at: https://www.health.ny.gov/health_care/medicaid/redesign/mrt_61.htm.

[v] http://www1.nyc.gov/site/dca/about/paid-sick-leave-law.page

[vi] http://www.labor.ny.gov/workerprotection/laborstandards/workprot/minwage.shtm

[vii] See FLSA Facts: Understanding the Revised Companionship Exemption http://phinational.org/fact-sheets/flsa-facts-understanding-revised-companionship-exemption. Currently, the U.S. Supreme Court is still considering whether to hear a challenge to the new companionship exemption rule.

[viii] Andryeyeva v. New York Health Care d.b.a New York Home Attendant Agency, Decision and Order February 19, 2013 and Opinion September 16, 2014, 2014 WL 4650233 (N.Y. Sup. Ct. 9/16/2014); Moreno v. Future Care, 2015 WL 1969753*4, 43 Misc. 3d. 1202 (N.Y. Sup. Ct. Kings Cnty. May 4, 2015)

[ix] See: https://www.health.ny.gov/professionals/home_care/hhtap_training_materials.htm

[x] PHI, "NYC Council Speaker Proposes Division of Paid Care." Accessed on February 16, 2016 at: http://phinational.org/blogs/nyc-council-speaker-proposes-division-paid-care

[xi] Int 1084-2016, NYC Council. Accessed on March 29, 2016 at: http://legistar.council.nyc.gov/LegislationDetail.aspx?ID=2576392&GUID=632A3331-9DC6-4348-ADB6-AD9FFF5F03A7

Are You Caring for Someone?

FOR THE RECORD

PSS

CIRCLE OF CARE

In New York City, 1.25 million family caregivers provide over one billion hours of unpaid care to elderly loved ones.

There are 425,000 caregivers in New York City helping family members with Alzheimer's Disease and other dementias.

Two out of every three working family caregivers report feeling chronic, long-term stress.

SOMETIMES CAREGIVERS JUST NEED A HELPING HAND
THAT'S WHY WE HAVE CIRCLE OF CARE

We understand that caregiving isn't easy. Caring for a loved one is a rewarding experience, but if caregivers don't get the help they need or don't take care of themselves, caregiving stress can affect their own health and well-being and lead to burnout. This is especially true for those caring for a loved one with dementia where chronic stress is associated with poor physical, psychological and emotional health.

Circle of Care is here to make it easier for you by providing support services that help you manage stress, including feeling overwhelmed, depressed, anxious, angry, exhausted, or even physically ill, as well as experiencing financial worries due to caregiving expenses or fear of job loss.

Circle of Care recognizes, respects, and values your role as a caregiver. We're here to help you meet your challenges, and we'll do all we can to assist you in caring for your loved one.

If you do ANY of the following for a loved one, YOU are a family caregiver:

- Provide unpaid assistance with tasks of daily living
- Offer emotional support and ensure a loved one's safety
- Frequently check up on your loved one by telephone or in person
- Provide transportation for medical appointments, shopping or recreation
- Shop for food and/or prepare meals
- Pay bills and attend to other financial matters
- Act as an advocate and access resources
- Help with household chores and repairs
- Coordinate medical care, monitor and/or administer medications

Recognizing that you are a caregiver is the first step toward receiving the support you need and deserve.

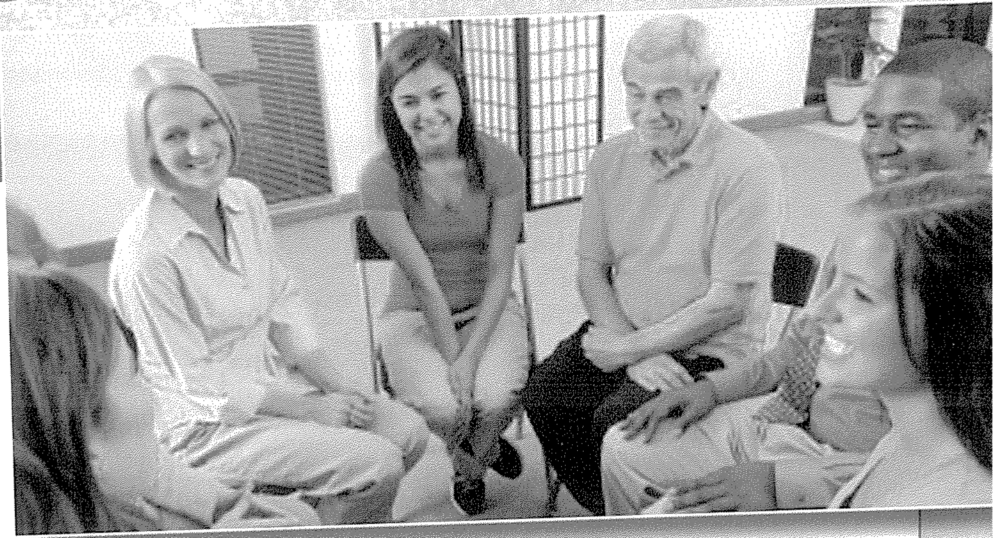
Carole M: *"I needed help and didn't know where to turn until I heard about Circle of Care. After I joined Circle of Care, I could pick up the phone anytime I needed to talk. Circle of Care was always there for me in a timely manner. The staff were extremely well-informed and responsive. On a scale of 1 – 10, my level of comfort with the staff -- make it a 12! At our home visit, my mom and I were received with warmth and respect. I would absolutely refer other caregivers to the program … so far I have referred three!"*

Call our Toll Free Hotline (866) 665-1713 **Services Available in All Five Boroughs**

JPSS CIRCLE OF CARE

SOMETIMES CAREGIVERS
JUST NEED
A HELPING HAND

WHAT CAN CIRCLE OF CARE DO FOR YOU?



- Our staff provide guidance to family caregivers at our **Circle of Care Stations** throughout NYC or in the client's home
- Information and referral – answers to your questions when you need them
- Assistance with vital benefits and entitlements
- Caregiver Support Groups available in person, by phone and online
- Training and online resources for caregivers of those with Alzheimer's Disease and other dementias
- Referrals for temporary respite (e.g., in-home care, adult day services) and supplemental services (assistive devices, health supplies, transportation, etc.)
- Bilingual support including ***Circulo de Cuidado***, a Spanish language blog providing resources, timely articles, and other items

Jacqueline H: *"I don't know if I am typical, but because David's dementia developed slowly over a period of 15 years, I thought I had everything under control. I soon learned that this was hardly the case. Circle of Care staff was a dream come true, always there with advice, guidance and homecare help. I could not have made it without them!"*

Call our Toll Free Hotline (866) 665-1713
Llame a Nuestro Teléfono Gratuito (866) 665-1713
Services Available in All Five Boroughs

JPSS CIRCLE OF CARE

Circle of Care is supported by grants from the New York State Department of Health Alzheimer's Disease Program and the U. S. Administration on Aging's National Family Caregiver Support Program through the New York City Department for the Aging.

PSS

CIRCLE OF CARE

Know the warning signs of Alzheimer's Disease and other Dementias

- Memory loss that disrupts daily life
- Difficulty completing familiar tasks
- Vision problems, unfocused staring
- Misplacing things, forgetting their function
- Changes in judgment, decision making, sense of humor, making poor financial decisions
- Frequent falling
- Confusion about dates and times
- Failing to find words
- Eating inappropriate items
- Withdrawal from work or social activities
- Mood, personality or behavioral changes

Don't ignore these changes – seek medical attention for early treatment for your loved one.

If you are caring for a frail or chronically ill family member or someone with Alzheimer's Disease or other dementias

Call our Toll Free Hotline (866) 665-1713
Llame a Nuestro Teléfono Gratuito (866) 665-1713
Or contact us via email at careinfo@pssusa.org

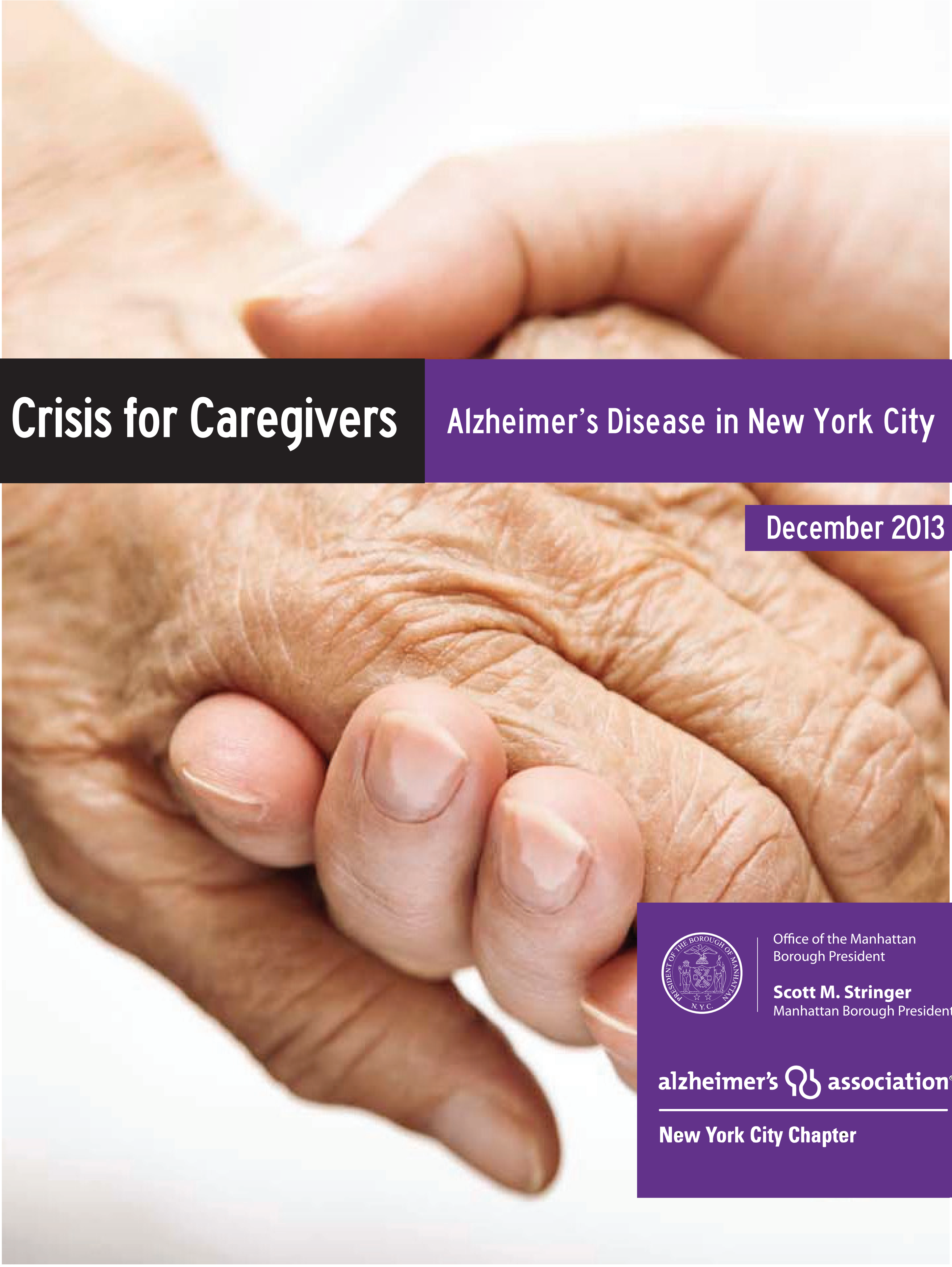
Circle of Care Stations are conveniently located in all five boroughs of New York. Please contact us for a location near you.

Are your members or employees struggling with caregiving responsibilities?
Circle of Care offers expert consulting and training on caregiving and related issues to companies and organizations. Please call our hotline or email us at careinfo@pssusa.org to discuss how we can help.

PSS CIRCLE OF CARE

Circle of Care
Locations in All Five NYC Boroughs
www.pssusa.org
Visit us at Facebook.com/PSSCaregivers

Call our Toll Free Hotline (866) 665-1713



Crisis for Caregivers

Alzheimer's Disease in New York City

December 2013

Office of the Manhattan
Borough President

Scott M. Stringer
Manhattan Borough President

alzheimer's association®

New York City Chapter

ACKNOWLEDGEMENTS

Borough President Stringer would like to thank Jessica Silver, Director of Community Affairs and Constituent Services, who was the primary researcher and writer of this report. He is also grateful to Stephen Corson, Deputy Director of Policy and Research, for his substantial contributions including data analysis and to Sabina Brukner, volunteer, who was instrumental in researching and reviewing the report.

Significant contributions to the report were also made by: David Saltonstall (Director of Policy and Research), Andrew Kalloch (Policy Analyst and Deputy General Counsel), Erin McGill and Adam Eckstein (Policy Analysts), Daniel Benjoya (Strategic Planner), Rebecca Godlewicz, Hannah Friedman, David Czyzyk and Kristen Ellis (Community Liaisons), Hunter Johansson (Special Assistant), Brian Cook (Director of Land Use and Planning), Sally Frank (Intergovernmental Affairs Liaison), Luisa González (Budget Coordinator), Josh Getlin (Director of Communications), Megan Dougherty (Press Secretary), Shannon Heath (New Media Associate), Nicole Turso (Speechwriter), Caesar-Robert Alfano (Graphic Artist), Samantha Lazar (Intern), Susannah Vickers (Director of Budget and Grants) and Alaina Gilligo (Chief of Staff).

Borough President Stringer would also like to thank Valerie Bogart, Director of the Evelyn Frank Legal Resources Program at the New York Legal Assistance Group, for her feedback and guidance.

The Alzheimer's Association, New York City Chapter would like to thank Jed A. Levine, Executive Vice President and Director of Programs and Services, for leading the Chapter's work on the report; Edward Cisek, Director of Program Evaluation, for his substantial contributions including his work on the survey instrument; Matt Kudish, Senior Vice President of Caregiver Services for his review and guidance, and Anne Foerg, Manager Care Consultation, for providing valuable input and guidance.

ABOUT REPORT PARTNERS

This report is a partnership between the Office of Manhattan Borough President Scott M. Stringer and the Alzheimer's Association, New York City Chapter.

During his nearly three decades in public service, Manhattan Borough President Scott M. Stringer has achieved tangible results for New Yorkers by forging diverse coalitions and addressing the City's most enduring urban challenges. He has dedicated himself to making New York City more affordable and livable, tackling issues such as housing, school overcrowding, public safety, sustainability and equal opportunities for underserved communities. The Borough President is a long time advocate for seniors and this report is an extension of his work on behalf of older New Yorkers.

The Alzheimer's Association, New York City Chapter is a founding member of the Alzheimer's Association – the world's largest voluntary health organization in Alzheimer's care, support and research. The New York City Chapter provides free information, confidential assistance and support for those with Alzheimer's disease and related dementias, as well as for their family members, caregivers and professionals. Core programs include a 24-hour Helpline, Care Consultation, Education and Training, Support Groups, Early Stage Services and MedicAlert® + Alzheimer's Association Safe Return®. The Chapter actively advocates at the city, state and federal level to support related legislation and heighten public awareness.

TABLE OF CONTENTS

I. EXECUTIVE SUMMARY

New York City's population is aging rapidly. The 2010 census found that almost 1 million New Yorkers are 65 years of age or older. By 2030, the New York City Department of City Planning estimates that over 1.3 million people will be aged 65 or older, an increase of 44.2 percent since 2000.[1]

With an older population comes a civic obligation to address health concerns associated with aging, including Alzheimer's disease – the sixth leading cause of death in the United States. While the City provides limited services for people with Alzheimer's disease and their caregivers, there is no comprehensive citywide plan. Available services fall woefully short of the demand, leaving many New Yorkers to suffer through this devastating illness with insufficient support.

In short, New York City stands unprepared to meet the growing public health and economic challenges posed by Alzheimer's disease. Instead, unpaid family caregivers often shoulder the burden of providing care and paying for Alzheimer's-related expenses, which often translates into lost wages, decreased mobility, and a tragic breakdown in family and social structures. Already, 40 states have recognized these challenges and have developed or are developing comprehensive plans to address Alzheimer's disease within their communities.

To better understand the impact of Alzheimer's disease on New York City residents, the Office of the Manhattan Borough President Scott M. Stringer and the Alzheimer's Association, New York City Chapter surveyed 496 city residents who serve as caregivers for friends or family members with Alzheimer's disease and related dementias in New York City.

The survey results were both alarming and eye-opening:

- **Caregivers spend significant amounts of time providing unpaid care to their friends or family member each week.** Over 40 percent of respondents are spending as many as 40 or more hours each week providing care for their family member or friend. For many respondents, caregiving duties have interrupted their ability to hold a job or changed the nature of the work they are able to do.

- **The majority of respondents missed work during the last year to provide care for their family members or friends.** Two-thirds of survey respondents indicated that they had missed at least one day of work in the last year to care for a relative or friend with Alzheimer's disease or related dementia. Over 17 percent had missed a staggering total of 21 or more days of work – equivalent to over four, full-time work weeks.

- **The majority of respondents have encountered barriers accessing some of the services required for their relatives or friends.** These barriers included a lack of insurance or insufficient insurance, the high cost of care, lack of local or appropriate services, unreliable transportation options, and daunting bureaucratic hurdles.

- **Respondents are deeply dissatisfied with the level of services and support available for people with Alzheimer's disease in New York City.** Half of survey respondents described the level of services and support available for people with Alzheimer's disease in New York City negatively, with over 35 percent describing them as "less than satisfactory" and almost 15 percent describing them as "poor." [2]

---

[1] http://www.nyc.gov/html/dcp/pdf/census/projections_report.pdf

[2] This finding does not correlate with the positive perception that clients of the Alzheimer's Association, NYC Chapter have expressed about the organization's services and programs. This finding reflects an overall impression of the options and accessibility of services in the city, as one organization cannot be charged with meeting the needs of all New Yorkers who require services.

- **The overwhelming majority of respondents – 95.5 percent – believe there needs to be a citywide plan to address Alzheimer's disease in New York City.**

The data suggests that despite the wide array of programs available in New York City, neither people with Alzheimer's disease nor their caregivers are receiving the services and support they need. The responses indicate insufficient services, poor quality care in residential settings and home health agencies, massive financial burdens on caregivers, and damaging emotional, health and professional effects to caregivers and their families.

Providing a high level of support for people with Alzheimer's disease and their caregivers – regardless of their economic position – will require changes at the municipal, state and national level.

This report offers the following recommendations, including but not limited to:

- **New York City should create an interdisciplinary task force to oversee the creation of a citywide Alzheimer's plan.** Relevant stakeholders including aging and health care experts should be appointed to the task force and charged with conducting an examination of the state of Alzheimer's care in the city and creating a set of plans and recommendations for improvements. Going forward, the City should consider expanding and reorganizing services to provide better outcomes for people with Alzheimer's disease, greater relief for their caregivers, and improved efficiency of the health care system overall.

- **Enhance training requirements for health care providers.** The New York State Department of Health should develop an expanded Home Health Aide and Home Attendant curriculum that teaches about the needs of people in all stages of Alzheimer's disease. Further, substantive dementia training should be provided for all staff that interacts with people with Alzheimer's disease in a range of health care and social service settings.

- **Expand funding for caregiver support services.** Caregivers suffer a tremendous emotional, physical and financial burden as a result of their caregiving responsibilities. By expanding services such as support groups, education and training, and financial and legal counseling, caregivers will be able to better care for themselves as well as their friends or family members, leading to increased overall health and wellness.

- **Create public information campaigns and expand "one-stop" centers.** The City should create public education campaigns that focus on recognizing the signs of Alzheimer's disease and where to turn for help, including the promotion of readily available but underutilized caregiver support services. The City should invest in publicizing two existing services – the Department for the Aging (DFTA) Alzheimer's and Caregiver Resource Center and the Alzheimer's Association 24-hour Helpline – and ensure they receive adequate resources to fulfill the demand for their services.

- **Improve quality and choice in community-based and residential services.** Improved services and care for people with Alzheimer's disease is desperately needed in both community-based and residential facilities. Day care, home care and respite programs allow families to keep their family members at home, which have demonstrated benefits for both the families and the individual living with Alzheimer's disease. The task force should explore ways to increase access to these in-home and neighborhood based services. The task force should also explore ways to improve the quality of dementia care and services in residential settings.

II. INTRODUCTION

New York City's population is rapidly aging. The 2010 census found that just over 17 percent of New Yorkers, or 1.4 million people, are 60 years of age or older – an increase of over 12 percent since 2000.[3] Just over 12 percent of New Yorkers, or 993,158 people, are currently 65 or older and this number is expected to rise significantly in the coming years.[4] By 2030, the New York City Department of City Planning estimates that over 1.3 million people will be aged 65 or older, an increase of 44.2 percent since 2000.[5]

With an older population comes an obligation to address health concerns associated with aging, including Alzheimer's disease and related dementias. The Alzheimer's Association estimates that one in eight older adults has Alzheimer's disease, making it the sixth leading cause of death in the United States and fifth among adults 65 to 85 years of age.[6] It is estimated that 250,000 people are living with Alzheimer's disease or related dementia in New York City.[7]

Alzheimer's disease impacts entire families, not just the individual with the disease. In 2011, it was estimated that 994,540 New Yorkers statewide were caregivers for someone with Alzheimer's disease or another form of dementia, providing an estimated 1.1 billion hours of unpaid care valued at $13.7 billion.[8] This caregiver burden creates significant impacts on the economic, physical and psychological health of hundreds of thousands of New Yorkers.

To better understand the impact of Alzheimer's disease on New York City residents, the Office of the Manhattan Borough President Scott M. Stringer and the Alzheimer's Association, New York City Chapter surveyed 496 city residents who serve as caregivers for friends or family members with Alzheimer's disease and related dementias. Their responses provided significant insight into how New York City must prepare to meet the needs of individuals with Alzheimer's disease, their families, and the health care community, and could serve as the basis for a future City planning process.

III. ALZHEIMER'S DISEASE

Alzheimer's disease is an irreversible, progressive brain disease. It is the most common form of dementia, and over time, destroys brain function. This leads to cognitive impairment, behavioral and psychiatric symptoms, and a decline in ability to function physically.

Difficulty with memory is often the first symptom of the disease. This mild cognitive impairment increases over time and can include forgetfulness, misplacing objects, and trouble with organization. By its mid-stages, Alzheimer's disease can lead to difficulty performing complex tasks, forgetting personal history, and changes in mood. As the disease progresses, individuals will experience impaired judgment, difficulty remembering their address or phone number, and confusion about where they are.

People with dementia experience severe cognitive decline during the later stages of the disease. They lose awareness of their surroundings, have trouble remembering people's names, require help getting dressed, experience significant behavioral changes, and are at risk of getting lost if left alone.

In the most advanced stage of the disease, individuals no longer recognize family members, lose their ability to talk or walk, and become incontinent. They require help with all aspects of personal care and their ability to swallow becomes impaired.

---

[3] http://www.nyc.gov/html/dfta/downloads/pdf/demographic/elderly_population_070912.pdf

[4] http://www.nyc.gov/html/dcp/pdf/census/census2010/t_sf1_p3_nyc.pdf

[5] http://www.nyc.gov/html/dcp/pdf/census/projections_report.pdf

[6] http://www.cdc.gov/nchs/data/nvsr/nvsr60/nvsr60_04.pdf

[7] This estimate, provided by the Alzheimer's Association, NYC chapter, is derived from other studies using national prevalence figures. All current Alzheimer's prevalence numbers are estimates based on different study populations, diagnosis methods and statistical models.

[8] https://www.alz.org/downloads/facts_figures_2012.pdf

The Manhattan Borough President's Office and the Alzheimer's Association, New York City Chapter forged a partnership to launch an online survey which was available to respondents from June 3, 2013 to September 16, 2013. The online survey received 496 distinct responses from caregivers who assist a family member or friend with Alzheimer's disease living in New York City. All survey data presented in this report is derived from these 496 respondents.

Overview of Findings

A. Satisfaction with available services

Among the top findings, approximately half of survey respondents described the level of services and support available for people with Alzheimer's disease in New York City negatively.[9]

- Over 35 percent described services and support as "less than satisfactory."
- Nearly 15 percent described services and support as "poor."
- Only 5 percent of respondents rated the availability of services as "excellent."

Among the survey respondents who volunteered their income information to researchers, middle class New Yorkers with reported incomes between $75,000 and $100,000 expressed the lowest levels of satisfaction with services and support, with approximately 61 percent of this cohort indicating that they found the level of available services and support to be either "poor" or "less than satisfactory."

This negative perception may be related to gaps in assistance for middle class New Yorkers whom neither qualify for public aid nor have the personal resources to provide the level of care their family members or friends need. One survey respondent summarized this dilemma, saying, "One of the major problems for the middle class is that a person with dementia, say a parent, may have too much money so are not entitled to social services, but not enough money to pay for private services."

Other survey respondents expressed frustration with the processes required to access services. According to one survey respondent, "My initial experience in getting my mother qualified for Medicaid was extremely frustrating. We never received a written approval letter and were advised months later after numerous telephone calls."

Another survey respondent suggested the need for "more services for people on fixed incomes who don't qualify for aid, yet can't afford to pay for services (home health/housekeeping) out of pocket."

At later points in the survey, a number of respondents discuss their dissatisfaction with the quality and quantity of care their friend or family member with Alzheimer's disease had been able to access. It is likely that the dissatisfaction with services being expressed stems at least in part from insufficient or poor quality home care, hospital care and residential care.

B. Amount of time required for care and missed work

For nearly half of the survey respondents, Alzheimer's care consumes almost as much time as a full-time job, in addition to all of the other life activities and obligations that survey respondents engage in each week.

- **Over 40 percent of respondents are spending 40 hours or more each week providing unpaid care for their family member or friend.**
- Nearly 8 percent of respondents report spending 31 to 40 hours caring for a relative or friend.

---

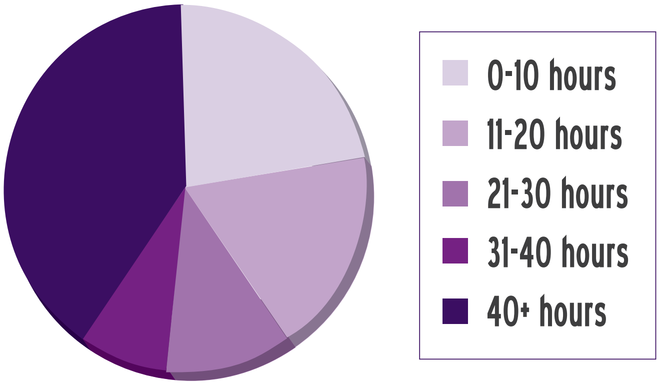
[9] This finding does not correlate with the positive perception that clients of the Alzheimer's Association, NYC Chapter have expressed about the organization's services and programs. This finding reflects an overall impression of the options and accessibility of services in the city, as one organization cannot be charged with meeting the needs of all New Yorkers who require services.

- Over 11 percent of respondents are spending 21 to 30 hours each week providing care.
- Over 18 percent of respondents provide 11 to 20 hours of care each week.
- Only 22 percent of respondents are providing 10 hours or less of care each week.

Figure 1 below illustrates the amount of time each week that survey respondents spend on caregiving duties.

FIGURE 1

Number of hours NYC residents spend providing unpaid care to a friend or family member with Alzheimer's disease or related dementias each week.



Unsurprisingly, the majority of respondents missed work during the last year to provide care for their family members or friends. Two-thirds of survey respondents indicated that they had missed at least one day of work in the last year to care for a relative or friend with Alzheimer's disease or related dementia.

- Over 23 percent of respondents indicated that they missed 1 to 5 days of work to care for a relative or friend with Alzheimer's disease.
- Over 43 percent of survey respondents reported missing over five days of work.
- **An alarming 17.5 percent of respondents indicated that they had to miss 21 days or more of work – more than four, full five-day work weeks – in order to care for a relative or friend with Alzheimer's disease.**

When responses to this question were filtered by reported incomes, **over 43 percent of respondents with incomes under $25,000 indicated that they had to miss 21 days or more of work**. This suggests that individuals with the fewest resources may be making the largest professional sacrifices in order to care for friends and family with Alzheimer's disease or related dementia.

Researchers also filtered the responses to this question to include only those aged 41 to 61, because these 215 respondents comprise the largest homogenous cohort of survey respondents.

Over 53 percent of respondents in the age 41 to 61 cohort reported missing over five days of work to care for a friend of family member with Alzheimer's disease, a level 10 percent higher than the total population of survey respondents.

Besides their considerable representation in this survey, the workplace impact on this cohort is important to understand because of the challenges that middle-aged workers face in today's modern economy.[10] Middle-aged workers are particularly prone to the negative consequences of Alzheimer's related work absences as they tend to have greater financial responsibilities than younger workers, often supporting children and in some cases, parents. Additionally, middle aged workers can face higher barriers to workplace re-entry after prolonged periods of unemployment than their junior colleagues.

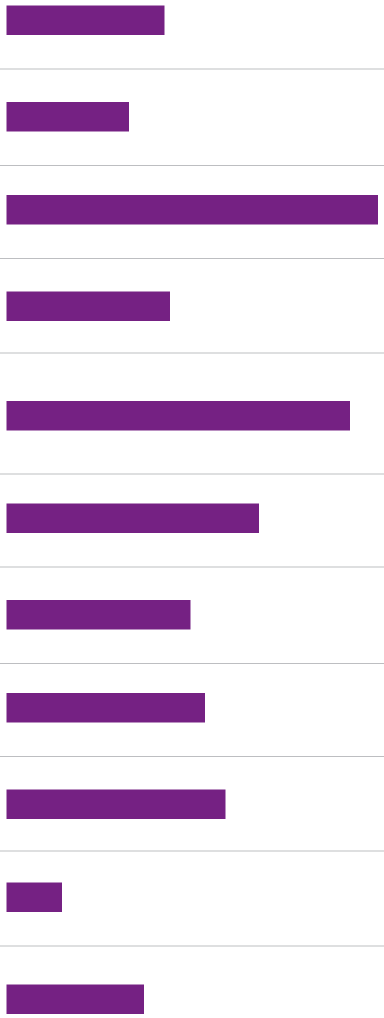
C. Utilization of services and barriers to access

Respondents are utilizing a range of services to help care for their relatives or friends. Survey respondents were provided with nine different service options and asked to mark all of the services that they had utilized. Among the responses received, 55 percent of respondents utilized home care services, which were utilized more than any other service. Over 50 percent of respondents used the services of a physician providing ongoing dementia related treatment. Figure 2 below illustrates the responses that were received from survey respondents.

---

[10] http://www.npr.org/2011/09/28/140847054/recession-a-tougher-hit-for-the-middle-aged

FIGURE 2



What services have you utilized to help care for a relative or friend with alzheimer's disease or related dementia in NYC?	Response Percent	Response Count
Adult Day Program - either social or medical	22.6%	112
Residential Care	17.9%	89
Home Care/Visiting Nurse Service	**55.0%**	**273**
Diagnostic Center/diagnosing physician	24.0%	119
Physician providing ongoing dementia related treatment	50.6%	251
Pharmacist	37.1%	184
Physical therapist/occupational therapist	27.0%	134
Legal/Financial Service	28.2%	140
Information & Referral Services	32.3%	160
None	7.9%	39
Other (please specify)	19.8%	98
	answered question	496
	skipped question	0

Despite the wide variety of services that survey respondents reported utilizing, the majority of respondents have encountered barriers to accessing some of the services required for their relatives or friends.

- Over 32 percent could not afford services or did not have insurance.
- Over 11 percent could not find the services they needed within their communities.
- Over 8 percent could not obtain transportation to the program/service.
- Over 5 percent found that the needed programs were full to capacity.

Additionally, 200 survey respondents opted to provide open-ended responses when asked: "If you have been able to utilize some services your relative or friend needs but not others, please provide a brief explanation of the service/s needed and the barriers you have experienced while trying to access it." A research team at the Borough President's Office reviewed open-ended responses by using a qualitative coding method.

One hundred open-ended responses described different barriers to access, with inadequate service options among the most cited. Responses include:

> *"Home Care services provided by long term plan is atrocious. These home aides are not properly trained in taking care of Alzheimer's / mentally challenged patients."*

> *"My mother would benefit from going to an activity based program for 2 hours / day to increase socialization but I find that most of the program hours don't align with my mother's schedule so we haven't utilized any."*

An additional 60 responses to this question cited personal and public funding short falls as a barrier to accessing Alzheimer's services in New York City. Examples include:

> *"Assisted Living is private pay only and does not accept any Medicare or insurance of any kind. This is a heavy financial burden. Cost of assisted living is less than a nursing home so it would benefit the government to allow Medicare to help."*

> *"Most of the programs require Medicaid. I can only afford for my mom to attend 3 hours a day twice a week at $75.00 per day/$25.00 per hour."*

Open-ended responses to this question also cited transportation barriers, language barriers, overwhelming amounts of paperwork, a lack of available services in the neighborhood, and a lack of information about what services are available.

For example, one survey respondent suggested that there should be "more resources about what services are available at various price levels. A website with reference material and listings would be helpful." Another noted that "information about the hospice service for the terminal patient with Alzheimer's disease or dementia was insufficient to us."

In addition to services for friends and family members with Alzheimer's disease, half of survey respondents indicated that they have used caregiver support services. Among the members of that cohort that indicated which services they have utilized:

- Over 61 percent indicated that they had participated in a support group.[11]
- Over 30 percent indicated that they had taken advantage of caregiver referrals.
- Over 28 percent indicated that they had attended counseling.
- Nearly 17 percent indicated that they had used respite services.

This data suggests that services for caregivers are well-utilized by survey respondents, indicating high demand. Respondents also spoke to the social value of utilizing these services, with one saying, "The best assistance I have received has been through fellow caregivers and support groups."

D. Financial Impacts: "Devastating"

Caregivers often experience significant financial burdens as a result of their duties, such as loss of employment or difficulty working full time. These duties can include taking the person they are caring for to medical appointments, covering for home health aides during off hours, and spending time learning to navigate health care systems and locate resources. They may also experience problems obtaining or keeping health insurance due to job loss, in addition to the financial strain of paying for the medical services of the person with dementia who is in their care.

Of the 496 survey participants, 383 answered the question, "In your own words, please describe the *financial* impact that having a relative with Alzheimer's disease or related dementia has had on you and the

---

[11] This number may be artificially high because many survey respondents were identified through the Alzheimer's Association, New York City Chapter which runs support groups. The Association estimates that 800 – 1,200 people participate in caregiver support groups citywide.

rest of your family." A number of respondents chose the word "devastating" to describe the impact on their finances.

While many respondents indicated that they had lost wages due to missed days of work, almost 10 percent of impacted respondents either lost their jobs altogether or were forced to retire early as a result of their caregiving duties. Continuing to work while caring for a relative or friend was simply not an option. Their comments include:

> *"I have become a stay-at-home caregiver. I've given up a middle income salary to care for my relative full-time."*

> *"I am unable to work outside my home. I work at home whenever possible but it does not support our family. My husband is unable to work and so our finances are very tight. I have applied for food stamps and am awaiting a response at this time."*

Other respondents noted the high cost of care and how it has impacted their relative or friend's financial stability as well as their own. Home health care, live-in care, and assisted living were some of the most burdensome costs noted. Examples of these responses include:

> *"I paid for one full year, $5,500 a month at [facility] before my mother was able to become eligible for Medicaid. I paid thousands of dollars to an elder attorney to facilitate my mother's acceptance to Medicaid so that I would not lose all the money that had been set aside for me, her only child. I took care of my mother at home for six years spending thousands of dollars for in home care prior to entering [facility]."*

> *"The financial impact is devastating. We do not have long term insurance, and we do not yet qualify for Medicaid. We have to spend down all of our savings to reach the $14,000 in allowable assets in order to qualify for Medicaid. Taking care of my husband will potentially leave me destitute, and unable to care for myself if - God forbid - I develop the same horrendous disease."*[12]

E. Non-financial impacts

Caregiving can take a serious toll on the physical and mental health of caregivers. It is not uncommon for caregivers to neglect their own health as a result of their caregiving duties. This can lead to fatigue, illness and depression. When caregivers experience poor health, it can lead to the premature placement of their relative in a nursing home.

Of the 496 survey participants, 416 answered the question, "In your own words, please describe the *non-financial* impact that having a relative with Alzheimer's disease or related dementia has had on you and the rest of your family." The respondents described a host of negative impacts including stress, depression, less time for their families, damaged relationships with their families, limited time to take care of their own well being, social isolation, exhaustion, and loss of their own physical and mental health.

Some of their responses include:

> *"Having to make a choice on a day to day basis whether to choose between my parents and my husband and children is a choice no one should have to make. I sacrificed experiences of my children growing that can never be replaced. I had to choose between helping my son with his homework or care for my parents...I was basically an absent parent and wife for several years."*

> *"The biggest change in my life is that I do not see friends often. I miss that. With working full-time and having a husband and step-daughter, I can't do it all."*

> *"Unable to take vacations. Over night stays or day trips, require too much covert planning, so I've just given up trying to take time off. This has*

---

[12] There are financial strategies to avoid "spending down" to qualify for Medicaid. The fact that many people are unaware of these strategies highlights the need for increased education.

> *increased my stress levels and I believe may have led to my cancer diagnosis and extreme weight gain. I can no longer go to the gym regularly since I have no income to spare for membership fees."*

> *"My husband was diagnosed with this disease almost 9 years ago, and it has consumed both of our lives. I still work, and the hours I am not working are totally spent on my husband's care. I will have to rebuild my own life from scratch when my husband does die. We have had no social life, our home is no longer a home - taken over by the materials and supplies necessary to take care of him. …Further, the stages my husband has been thru have been emotionally wrenching, and frightening. …It has been a living, endless nightmare. To top it off, I'm worried about the effect all this stress is having on my own health, and what kind of financial shape I'm going to be left in when my husband does die."*

Excessive burdens are clearly being placed on unpaid family caregivers who do not have the resources, training or support to care for their friend or family member. As a result, not only are people with Alzheimer's disease at risk of sub-standard care, but the health and economic stability of their families and friends are jeopardized, creating broader impacts on the public and economic health in our city.

F. Feedback on a citywide plan for Alzheimer's disease

Rounding out the survey, **the overwhelming majority of respondents – 95.5 percent – believe there needs to be a citywide plan to address Alzheimer's disease in New York City.**

Adding additional context to the near unanimous call for the establishment of a citywide plan, 329 survey respondents provided optional responses to the following open ended question: "If you answered 'Yes – there needs to be a citywide plan to address Alzheimer's disease or related dementia', what issues would you like to see addressed/what recommendations would you provide?" Open ended responses were reviewed by a research team at the Borough President's Office using a qualitative coding method.

Responses were categorized using the broad categories of:

1) **Affordability**
2) **Services and Care for People with Alzheimer's**
3) **Services for Caregivers**
4) **Cutting Red Tape**
5) **Information**
6) **Research**

Within those broad categories, responses were sub-categorized into more specific categories. Table 3 below illustrates the responses by broad category and shows that respondents believe that improving services and care for people with Alzheimer's disease should be a top priority for any future citywide plan.

Among the specific sub-categories:

- **Increased or improved in-home services** were cited in 27 different responses.
- **Improved training or support for home health aides and increased funding for in-home services and programs** were each cited in 25 different responses.
- **Training and support services for friends and family providing care** were cited in 35 different responses.

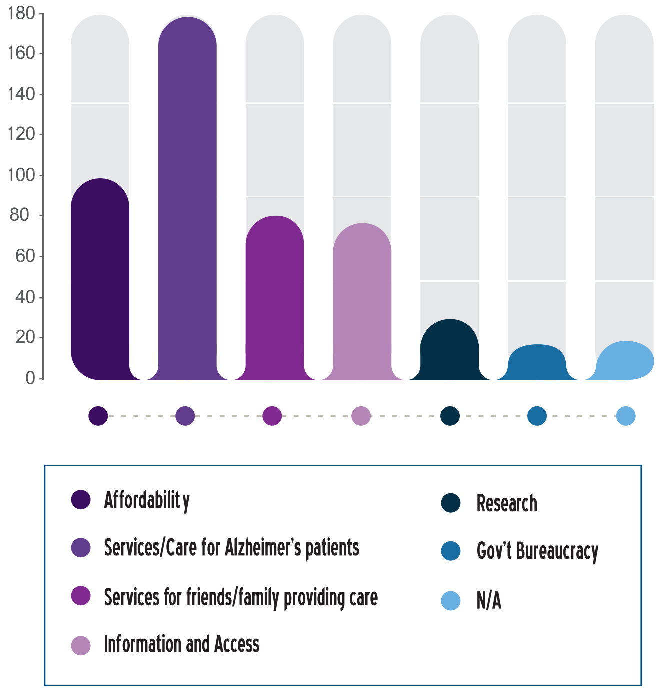
This suggests that there is a strong demand among survey respondents for more robust non-institutional care options for people with Alzheimer's disease. Additionally, these results clearly indicate that education and training for family caregivers, health care workers, and professionals across disciplines must be prioritized in a future citywide plan.

One respondent shared the following anecdote illustrating the need for training in hospitals, "There should be some emphasis placed in the training of attendants at hospitals. Once I found my husband stark naked and the attendant was just sitting there talking to another colleague. I was heartbroken."

Another offered the following recommendation, “Training health care workers such as health aides to understand and manage the symptoms is essential as we face an epidemic of dementia as the population ages.”

FIGURE 3

Issues that respondents believe a citywide Alzheimer’s disease plan should address, by number of responses.



V. EXISTING PLANS TO ADDRESS ALZHEIMER’S DISEASE

The need for forward thinking, comprehensive planning to address Alzheimer’s disease has been acknowledged at the national, state and municipal levels. Several significant planning efforts have already been undertaken. New York City can learn from these initiatives in its own efforts to plan for its residents.

National Plan

In 2012, the Obama Administration released a ***National Plan to Address Alzheimer’s Disease.***[13] This plan was required by the bipartisan National Alzheimer’s Project Act which President Obama signed into law in 2011 and includes five key goals:

1) Prevent and effectively cure Alzheimer’s disease by 2025;
2) Enhance care quality and efficiency;
3) Expand support for people with Alzheimer’s disease and their families;
4) Boost public awareness and engagement; and
5) Improve data to track progress.

The 2013 update to the plan includes action steps to achieve a sixth goal: prevention of elder abuse against those with Alzheimer’s disease.[14]

The plan charges the U.S. Department of Health and Human Services with expanded efforts to achieve these goals in cooperation with other federal agencies such as the Department of Veterans Affairs and the Health Resources and Services Administration, states, and other stakeholders.

A New York State Framework

The New York State Coordinating Council for Services Related to Alzheimer’s Disease and Other Dementias, a group that works under the auspices of the New York State Office for the Aging, identified a number of best practices and recommendations in its 2009 Annual Report to Governor David Paterson and the New York State Legislature.[15] These recommendations were informed by a series of community forums held throughout the State, one of which was held in Manhattan.

Key recommendations of the report include: education for employers and caregivers, increased access to respite, developing specialized training in dementia diagnosis and treatment, requiring training for hospital staff, and promoting programs that integrate health and social services. Additional recommendations pertaining to early detection were highlighted in a 2011 supplemental report to Governor Andrew Cuomo.[16]

---

[13] http://aspe.hhs.gov/daltcp/napa/NatlPlan.pdf

[14] http://aspe.hhs.gov/daltcp/napa/NatlPlan2013.pdf

[15] https://www.alz.org/national/documents/ny_report.pdf

[16] http://www.health.ny.gov/diseases/conditions/dementia/reports/docs/2011_coordinating_council_annual_report.pdf

The San Francisco Model

The City of San Francisco undertook a comprehensive planning process to address Alzheimer's disease in 2009.[17] At the behest of then-Mayor Gavin Newsom, San Francisco's Department of Aging and Adult Services undertook a seven-month planning process that engaged public health officials, hospital administrators, homecare experts, medical providers, researchers, economic experts, experts in Alzheimer's disease, family caregivers and older adults in an "Expert Panel."

In addition, a research team conducted an evaluation of the city's dementia services, compiled the recommendations of the expert panel, and drafted ***2020 Foresight: San Francisco's Strategy for Excellence in Dementia Care.***[18] This report focuses on the city's specific demographics, assets and challenges and provides an understanding of the scope of the disease's effects and needs. Additionally, it offers a framework of recommendations upon which work in other cities, such as New York can be based.

The main objectives of the report include: expanding capacity to deliver early diagnosis, expanding and improving the quality of community-based care for people with dementia, improving public and professional awareness of dementia, and expanding the range of models of residential care.

Other States

According to the Alzheimer's Association, 31 states have plans to address Alzheimer's disease, with 12 additional states and the District of Columbia in the process of writing such plans. The state plans can be compared in a report by the Alzheimer's Association, ***State Alzheimer's Disease Plans*** or state plans can be accessed individually.[19] Many recommendations in these plans may be applicable to New York City including:

- Develop and post on the web a "tool box" of promising practices for physicians for detecting and diagnosing people with Alzheimer's disease. **(Michigan)**
- Strengthen primary care practices by dedicating staff support to coordinate care, manage individual cases, and develop formal mechanisms for referral to health care homes and community-based agencies that offer specialized expertise, social supports, and mental health services. **(California)**
- Work with Congress to eliminate barriers (such as Medicare's two-year waiting period) for people with early onset Alzheimer's disease to receive federal benefits. **(Illinois)**
- Establish Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease and other dementias and their caregivers. **(Iowa)**
- Ensure that Alzheimer's disease and other dementias are identified as one of the chronic conditions in the Affordable Care Act and other funding sources' criteria that are used to identify people eligible for services, including home health services. **(Maine)**
- Convene a workgroup of physicians and other mental health and Alzheimer's disease specialists to determine the adequacy of geriatric-psychiatric hospitals and to establish a consensus plan outlining parameters for the type and length of treatment that should be provided to people with Alzheimer's disease. **(Illinois)**
- Explore options to increase insurance coverage for individuals with Alzheimer's disease and other dementias, including: (1) ensuring Medicaid eligibility for individuals with younger-onset Alzheimer's and other dementias; (2) the potential for an Alzheimer's and other dementias-specific Medicaid waiver; and (3) services and options available under private insurance. **(Kentucky)**

---

[17] http://www.sfhealthyaging.org/city-hall-summits/14-2/
[18] http://www.sfhsa.org/1439.htm
[19] http://act.alz.org/site/DocServer/STATE_AD_PLANS.pdf?docID=4641

- Create a state certification in dementia care for facilities, agencies, and individuals licensed and monitored by the Colorado Department of Health and the Environment and the state health professions' licensing boards. **(Colorado)**

- Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies, and stipends) to increase the number of health care professionals who pursue education and training to specialize in gerontology and geriatrics. **(California)**

- Provide financial incentives (e.g. tax credits or deductions) to help family members keep individuals with Alzheimer's disease and other dementias at home longer before institutionalizing them, thus reducing Medicaid outlays. **(Idaho)**

VI. RECOMMENDATIONS

As the population continues to age, the City must ensure it is prepared to meet the needs of its seniors and their families. The survey results in this report demonstrate a clear need for better services and support for people with dementia and their caregivers. **Rather than approaching this challenge in a piecemeal fashion, New York City should invest resources into designing a comprehensive strategy to address the growing impact of Alzheimer's disease on its residents in the coming years.**

In order to be effective, the plan must be far-reaching and include all parties involved in Alzheimer's care and service delivery. This effort should start with the creation of an interdisciplinary task force that can conduct a thorough examination of the state of Alzheimer's care in the city, create a set of plans and recommendations for improvements, and then work with relevant City and State agencies, hospitals, health care providers, and community-based organizations to implement a comprehensive citywide Alzheimer's disease strategy.

The following recommendations should be at the core of such an initiative.

Planning and Innovation

- **New York City should create an interdisciplinary task force to oversee the creation of a comprehensive city-wide Alzheimer's strategy.** The Department for the Aging, the Department of Health and Mental Hygiene and the Alzheimer's Association NYC Chapter should be charged with leadership roles in this undertaking, and subsequently with driving forward the City's Alzheimer's policy agenda, services and programs. Gerontologists, hospital administrators, nursing home administrators, experts in home health care, researchers, medical care providers, and family caregivers should be represented on the taskforce, among others.

- **Create a comprehensive inventory of community-based programs and services available to people with Alzheimer's disease and caregivers in New York City.** The City's interdisciplinary task force should make it a priority to identify service gaps among the existing resources and recommend how programs can be expanded or created to fill these gaps. This inventory should be broken down by neighborhood to identify where communities lack specific services and where improved transportation connections can help increase access to programs.

- **Examine opportunities to streamline services and provide for improved continuum of care.** Improvements to continuum of care will provide better outcomes for people with Alzheimer's disease, greater relief for their caregivers, and improved efficiency of the health care system overall. Focus should be placed on the integration of comprehensive care services and tracking people with Alzheimer's disease over time. Seamless care services should be available from the point of diagnosis through end-of-life care.

- **The NYC Department of Health and Mental Hygiene should begin allocating resources to address the public health impacts of Alzheimer's disease.** Currently, DOHMH has no dedicated staff or resources focused on Alzheimer's disease. This is a missed opportunity in tackling the disease comprehensively. The Department should consider creating an Alzheimer's unit – or other appropriate organizational structure – to gather information and data about New York City's Alzheimer's population. With enhanced information-gathering capabilities, the City will be better equipped to make data-driven decisions that will help support those that must cope with Alzheimer's disease.

Education and Training

- **Create public education campaigns focused on recognizing the early signs of Alzheimer's disease.** Despite increases in the prevalence of Alzheimer's disease, many people are unaware of the warning signs, and as a result miss the opportunity for early interventions. Public awareness campaigns would educate New Yorkers about how to recognize signs of dementia and where to turn for help.

- **Require expanded Alzheimer's training as a component of the Home Health Aide and Home Attendant Training Programs offered in New York State.** New York State requires certified home attendants to complete at least 40 hours of training. Home health aides must complete an additional 35 hours of training for a total of 75 hours, including 16 hours of supervised practical training. Only two hours of the curriculum are currently devoted to aging issues, and while discussion of mental functioning is included within those two hours, there is no specific component on Alzheimer's disease or dementia. The New York State Department of Health should develop an expanded curriculum that includes instruction on the physical and mental health needs of people with Alzheimer's disease in all stages. Successful completion of this new Alzheimer's component should be required in order to receive certification as a home attendant or home health aide.

- **Require training for staff that work with people with Alzheimer's in a range of settings including hospitals, nursing homes, assisted living facilities and community-based agencies.** Care quality can be enhanced significantly through increased education and training. Substantive training should be provided for all health care staff that interacts with people diagnosed with Alzheimer's disease – not just medical professionals. This new training should focus on the symptoms of dementia, early detection, diagnosis, treatment and sensitivity training for working with people with Alzheimer's disease and their families. All training should include culturally appropriate strategies to serve New York City's diverse ethnic and linguistic communities.

Services and Care for People with Alzheimer's disease

- **Medicaid home care service options should be expanded in New York State to accommodate a broader range of needs for people with Alzheimer's disease and related dementias.** New York State's Medicaid plan includes home care services; however, the type and level of authorized services can fail to meet the needs of people with Alzheimer's disease. The State should explore broadening Medicaid eligible services to include safety monitoring such as cueing and orienting - even when it is the only required service - to ensure the needs of those in earlier stages of the disease are met. Further, although there is no limit on the number of homecare hours provided by Medicaid, in practice, many families receive fewer approved hours than they truly require. The number of home care hours provided by Medicaid should be increased when needed to support not only the person with Alzheimer's disease, but their caregiver as well.

- **Enhance the quality of care for people with Alzheimer's disease or related dementias in residential settings, including Assisted Living Facilities and nursing homes.** Improved care for people with Alzheimer's is desperately needed in residential facilities. This starts with improved training for all staff members but extends to the implementations of best practices in dementia care, a wider range of programmatic options, and improved oversight.

- **Create new programs to serve a broader segment of people with Alzheimer's disease and caregivers.** Many survey respondents expressed a need for programs for people in the early stages of the disease and for families and people with Alzheimer's disease to participate in together. The City can encourage the creation of such programs by providing funding to agencies that offer programs meeting these criteria. This would ensure a greater number of programs are equipped to serve people with Alzheimer's disease with progressing symptoms.

- **Expand funding for programs that keep people with Alzheimer's disease in community settings as long as possible.** Day care, home care and respite programs allow families to keep their friend or relative with Alzheimer's disease at home. This can be important to the health and well-being of a person with Alzheimer's as it minimizes the confusion that can accompany transitions and allows for one-to-one care, which is not possible in an institutional setting. However, access to these programs and affordability of care prevent many families from utilizing services they need. The task force should explore ways to increase access to neighborhood services.

- **Naturally Occurring Retirement Communities (NORCs) should be better utilized as partners in early detection and treatment for Alzheimer's disease.** New York City has a number of successful NORC programs, encouraged and funded by the NYC Department for the Aging. As NORCs literally meet seniors where they are – within their own building complexes and communities – they are in a unique position to encourage cognitive screenings, monitor changes in behavior, and facilitate the provision of on-site services for those in need of care. The City should explore a deeper partnership with NORCs to promote early detection and access to services.

Services for Caregivers

- **New York City should expand funding for caregiver support services.** Caregivers suffer tremendous emotional, physical and financial burdens as a result of their caregiving responsibilities. By expanding services such as support groups, education and training, financial counseling and legal guidance, caregivers will be able to better care for themselves as well as their friends or family members, leading to increased overall health and wellness.

- **Expand and promote "one-stop" centers for information and referrals for people with Alzheimer's disease and their caregivers in New York City.** New York City has two information and referral services for people with Alzheimer's disease and their caregivers, yet many survey respondents said they did not know where to turn for help. The City should invest in publicizing the two existing services – the DFTA Alzheimer's and Caregiver Resource Center, and the Alzheimer's Association 24-hour Helpline – and ensure they are adequately resourced to fulfill the demand for their services.

VII. METHODOLOGY AND LIMITATIONS

The survey used for this report was developed jointly by the Office of Manhattan Borough President Scott M. Stringer and the Alzheimer's Association, New York City Chapter. All survey questions are included in Appendix A.

The survey and its analysis have some modest limitations. First, because the survey was publicized by the Manhattan Borough President's Office and the Alzheimer's Association, New York City Chapter primarily using the respective contact lists of those two organizations, survey responses include a strong selection bias. There are two categories where this selection bias is particularly apparent – the high number of Manhattan residents that responded to the survey and the high number of respondents that participate in support groups, one of the most well-subscribed services provided by the Alzheimer's Association.

Additionally, a qualitative coding method was applied to two open-ended survey responses – question 9 and question 16 – in order to quantify responses to these questions. Therefore results of questions 9 and 16 are less reliable than other questions and should be considered anecdotal.

VIII. APPENDIX I: SURVEY INSTRUMENT

CAREGIVER SURVEY

This survey has been created by Manhattan Borough President Scott Stringer and the Alzheimer's Association, New York City Chapter to learn more about the experiences of people caring for those with Alzheimer's disease or dementia in New York City.

1. Who is the relative or friend you care for?
   - ☐ Parent
   - ☐ Spouse
   - ☐ Grandparent
   - ☐ Aunt/Uncle
   - ☐ Sibling
   - ☐ Cousin
   - ☐ Friend
   - ☐ Other (please specify)

2. Where do you care for this relative or friend?
   - ☐ In your own home
   - ☐ In their own home
   - ☐ In supportive housing/assisted living
   - ☐ In a nursing home
   - ☐ Other (please specify)

3. Where does your relative or friend with Alzheimer's disease live?
   - ☐ Manhattan
   - ☐ Brooklyn
   - ☐ Bronx
   - ☐ Queens
   - ☐ Staten Island
   - ☐ Other (please specify)

4. What is your opinion about the level of services and support available in NYC for people with Alzheimer's disease or related dementia and those who care for them?
   - ☐ Excellent
   - ☐ Very Good
   - ☐ Satisfactory
   - ☐ Less than satisfactory
   - ☐ Poor

5. How many hours per week do you typically spend caring for a relative or friend with Alzheimer's disease or related dementia?
   - ☐ 0 – 10 hours
   - ☐ 11 – 20 hours
   - ☐ 21 – 30 hours
   - ☐ 31 – 40 hours
   - ☐ More than 40 hours

6. How many days in the last year have you missed work to care for a relative or friend with Alzheimer's disease or related dementia?
   - ☐ 0 days
   - ☐ Between 1 and 5 days
   - ☐ Between 6 and 10 days
   - ☐ Between 11 and 20 days
   - ☐ 21 days or more

7. What services have you utilized to help care for a relative or friend with Alzheimer's disease or related dementia in NYC? [check all that apply]
   - ☐ Adult Day Program - either social or medical
   - ☐ Residential Care
   - ☐ Home Care/Visiting Nurse Service
   - ☐ Diagnostic Center/diagnosing physician
   - ☐ Physician providing ongoing dementia related treatment
   - ☐ Pharmacist
   - ☐ Physical therapist/occupational therapist
   - ☐ Legal/Financial Service
   - ☐ Information & Referral Services
   - ☐ Other (please specify)

8. If you have not utilized services to care for your relative or friend, please indicate the reasons why not. [check all that apply]
   - ☐ My relative/friend does not need any services
   - ☐ The services they need are not available in my community
   - ☐ They cannot afford the service/ do not have insurance
   - ☐ The program/s are full to capacity
   - ☐ The program/s are at an inconvenient time
   - ☐ There is no accessible transportation to the program/service
   - ☐ Other (please specify)

9. If you have been able to utilize some services your relative or friend needs but not others, please provide a brief explanation of the service/s needed and the barriers you have experienced while trying to access it.

10. How do you learn about the services that are available to your relative or friend with Alzheimer's disease or related dementia? Examples might include: the internet, referral to services by a physician, information provided by a friend, etc.

11. Have you or members of your family ever utilized caregiver support services?
    - ☐ Yes
    - ☐ No

12. If yes, please specify that type of service. [check all that apply]
    - ☐ Support Group
    - ☐ Respite Services
    - ☐ Counseling
    - ☐ Referrals
    - ☐ Other (please specify)

13. In your own words, please describe the financial impact that having a relative with Alzheimer's disease or related dementia has had on you and the rest of your family. Examples might include: lost wages due to missed work, co-pays for services covered by insurance, payment for services that are not covered by insurance, etc.

14. In your own words, please describe the non-financial impact that having a relative with Alzheimer's disease or related dementia has had on you and the rest of your family. Examples might include: increased stress, less time to spend with your family, less time to take care of your own health, etc.

15. Do you think there needs to be citywide plan to address Alzheimer's disease or related dementia?
    - ☐ Yes
    - ☐ No

16. If you answered yes, what issues would you like to see addressed/what recommendations would you provide?

17. Would you be willing to talk further about your experiences/concerns with a member of the Borough President's staff? If so, please provide your name and the best way to contact you.

18. Please provide the following demographic information:

Gender: ☐ Male ☐ Female ☐ Transgender ☐ I'd rather not say

Ethnicity:

- ☐ African American/Black
- ☐ Latino/Hispanic
- ☐ White/European
- ☐ South Asian
- ☐ I'd rather not say
- ☐ Caribbean/West Indian
- ☐ Asian/Pacific Islander
- ☐ Native American/American Indian
- ☐ Other

Age:

- ☐ Under 25
- ☐ 25 - 40
- ☐ 41 - 60
- ☐ 61 - 80
- ☐ 81+
- ☐ I'd rather not say

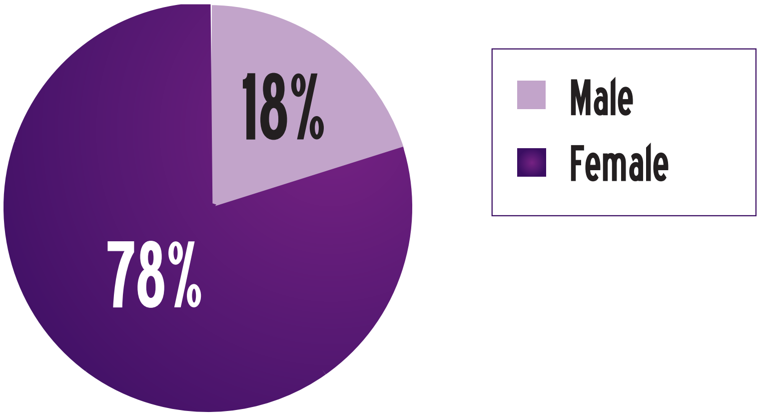
Income Bracket:

- ☐ Under $24,999
- ☐ $25,000 – $49,999
- ☐ $50,000 – $74,999
- ☐ $75,000 – $99,999
- ☐ Over $100,000
- ☐ I'd rather not say

IX. APPENDIX II: DETAILED DEMOGRAPHIC INFORMATION OF RESPONDENTS

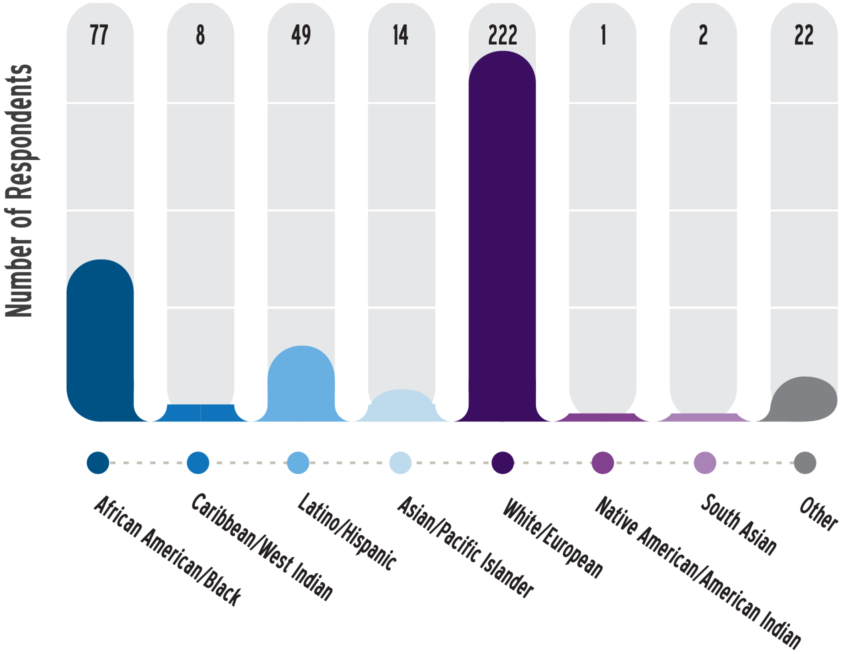
Of the 496 survey participants, 431 opted to provide their demographic information. Of those respondents, approximately 18 percent of respondents identified as male and approximately 78 percent of respondents identified as female.

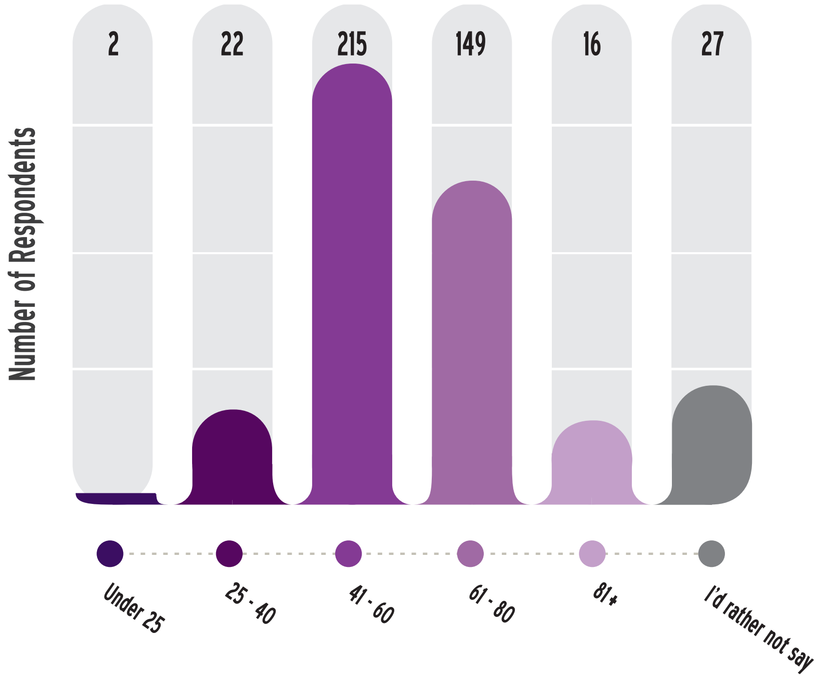
Gender of Survey Respondents



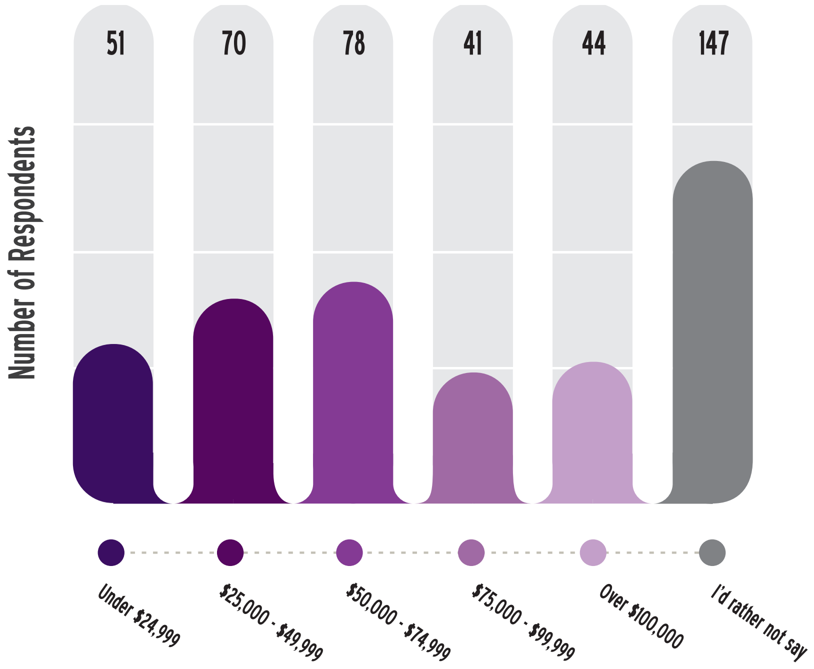
Survey respondents were also asked to provide information on race, age and income. These responses are summarized in the bar graphs below.

Race/Ethnicity of Survey Respondents





Age of Survey Respondents



Income Bracket of Survey Respondents

alzheimer's association®

New York City Chapter

360 Lexington Avenue, 4th floor, New York, NY 10017
24-hour Helpline: 800.272.3900
www.alz.org/nyc

@alznyc **Facebook.com/alznyc** **pinterest.com/alznyc**

SCOTT M. STRINGER
MANHATTAN BOROUGH PRESIDENT
Municipal Building One Centre Street, 19th Floor New York, NY 10007
Tel: 212.669.8300 Fax: 212.669.4306
www.mbpo.org

Visit our Manhattan Minute blog at www.mbpo.org/blog.asp

@scottmstringer **Facebook.com/scottstringernyc** **scottmstringer.tumblr.com**

My name is Teri Graham and I am the director of the Head Start Sponsoring Board Council. As important as it is to increase the pay for staff working in day care and head start, I'm here because for 3 years I was my mother's caregiver. She was diagnosed with dementia in 2013 after I noticed some disturbing changes.

Being a caregiver is a very difficult job. Many people can't handle it and many more don't even try. Unless you actually have done it you have no idea the physical, mental and emotional toll it takes. It is exhausting, isolating and as dementia progresses caregiving becomes an all-consuming task. You end up sacrificing everything to be there for someone else and it's rarely easy. No one could have foreseen this but dementia doesn't discriminate and as the population ages the incidents are growing exponentially. It is a cruel disease inflicting humiliation and indignities while robbing a person of their memories and quality of life. I would wake up, after a less than restful sleep and listen for the TV. My mother was always an early riser and dementia didn't change that. If I heard the TV, I willed myself to get up to get her breakfast and morning pill. Literally every part of my body ached because I was tired, worn out from the day before. If I didn't hear the TV, I still had to get up to find out if she was okay and see why she wasn't up. Eventually I was forced to hide the remote because she kept losing it along with the still missing telephone.

On rare occasions she would sleep in which meant a little more rest for me. If she was up, I dragged my weary body out to the living room and would peek around the corner to see what she was doing. If she was sitting quietly, I'd inspect the house, first the kitchen, dining room, etc. to make sure she didn't touch, burn or break anything. If everything seemed to be okay, I'd ask if she was hungry. Each night I defrosted her meals from God's Love We Deliver for the following day, placing them in microwave safe containers. They had to be defrosted in the refrigerator not room temperature. If there were mushrooms I'd pick out each one because she hated mushrooms. While she was eating I'd brush my teeth and return to bed while she ate. I'd wash the dishes and try to get some work done. If I was unusually lucky she'd spend the day watching TV and nothing eventful would happen. More likely she'd try to go down the stairs without her cane. This was an ongoing battle. Sometimes she'd be so angry that I reminded her not to go downstairs without the cane she'd slam the door and sit down to pout. During the day I'd give her snacks such as salt free potato chips, granola bars and Breyers sugar free ice cream. By the time I gave her dinner she'd claim she was starved and hadn't eaten all day even though she sat next to an empty potato chip bag, which she claimed someone else had eaten. Back then I was stupid enough to argue until the social worker told me you can never convince someone with dementia that they are wrong. It took ages for me to realize that using logic with someone who was no longer capable of being logical was a losing battle. I tried to keep her calm and out of trouble and prayed she'd be happy relaxing in the living room but she often had the compulsion to remove all the clothes from her closets and drawers which then had to be put back. I have no idea why she did it but it frustrated me because I couldn't stop her from doing it. However it was better than when she tried to drink French dressing or eat some outdated can of food which she tried to open with a knife.

At some point in the evening she would go to bed and I prayed she would stay there but as her dementia progressed, this was not the case. She would go to bed and I would breathe a sigh of relief that I could finally watch a movie or get something to eat but 15 minutes later she was up and making her bed. I tried three different prescriptions to help her sleep but NONE worked. The cycle of going to bed then getting up again sometimes lasted for hours each night when all I wanted to do was get some rest. My days extended from sun up to sun down. I couldn't sleep or eat or even shower. Once I was very sick but couldn't stay in bed to take care of myself because there wasn't anyone available to take care of my mother. It became impossible to plan anything because I never knew what curve ball she would throw me or more accurately the dementia would throw me. The stress became unbearable and resulted in headaches, backaches, nervous stomach, high blood pressure and my drug of choice binge eating.

Last March I was exhausted and placed her in respite care. The first week was harder than I imagined for me to adjust but the second week was better and I extended her stay for the maximum period of a month. I finally got some much needed uninterrupted sleep but even that took a while to get used to. I still listened for the TV to see if she was up or not. I railed on many occasions against being a caregiver especially since I have a sibling in

Boston who never made any effort to help with either time or money. It wasn't fair to ask me to sacrifice my life, plans and job to stay home tied to my mother 24/7. That didn't even include uncontrolled crying, yelling loudly in her sleep, hostility, threats, verbal abuse, 3 hours prep to go to the doctor and the increasing incontinence which was becoming intolerable. I used to lie awake at night dreaming about what it would be like to be free and have my life back. Just the freedom to take a walk without worrying about some disaster taking place in my absence would've been nice. I never went anywhere without checking my watch. As I approached the house my heart raced not knowing what I might find when I went inside. If I didn't accept my current job, I would've done whatever it took to keep my mother at home. I tried to get a permanent home health aide, most required 20-25 hours a week for no less than $20-25 an hour. It would cost extra for evenings, weekends and on holidays. Several agencies came to the house to do an evaluation and I tried about 3 different aides last year but we couldn't get approval. Then I tried adult day care which was fine if you qualify for Medicaid but since she didn't we were going to have to pay at least $90 a day for 6 hours which was not enough for me to work full time. I reluctantly had to place her in assisted living which cost more than $5000 a month. Yes it included food, utilities, medical visits but if I had to transport her to a different doctor, I had to pay extra, I paid for adult diapers which were costing a fortune until I decided to buy my own from CVS. I paid for all her toiletries, was billed for medication and anything else she needed so all in all I could have rented a luxury apartment in Manhattan for less. As expensive as this was for us, I was fortunate that my parents saved money, had pensions, social security and my mother had benefits from 30 years as a public school employee, but I burned through the money in my mother's checking account to keep her in assisted living. The threshold to qualify for Medicaid is too high and most people won't and don't make the cut so families not only carry the emotional and physical burden of being caregivers but they bear a huge financial burden, often quitting jobs to be there full time and losing income that they can never recover. I paid for the vans which too her from the assisted living facility to the hospital to the rehab and back again.

After being hospitalized last November she was transferred to a rehab facility which I will always regret. She wasn't doing well and I would leave work early, take the subway from Manhattan to Queens, then take a cab to the rehab facility so I could feed her. I didn't feel confident that anyone had the patience to feed her since it took a lot of time and prodding to get her to eat just a little bit. One Friday I arrived to find her strapped into her wheelchair, completely slumped over. I have no idea how long she was like that but my guess it was most if not all day. When I asked the aides sitting right there they suddenly lost the ability to speak and started pointing fingers at each other. She was completely soaked because no one had taken her to the bathroom. When I wheeled her back to her room, she was in agony being transferred from the chair to her bed. I asked for medical assistance and was told the doctor wouldn't be in until the next day which was Saturday. When I arrived on Saturday I was told the doctor wouldn't be available during the weekend. Eventually they took x-rays and no broken ribs. I never said there were broken ribs because it seemed the problem was her leg. I told the medical staff on several occasions her foot was swollen. The nurse said he didn't see any swelling even though they had her foot propped up on a pillow. By the time she was hospitalized again in December she had a blood clot which caused the intense pain in her foot. Repeatedly I told people she couldn't answer health questions due to her dementia yet they insisted on asking her questions and when I intervened or suggested having her tested for things like UTIs they acted like I was the one suffering with dementia.

My mother has been gone for almost 3 months now. I have my life back but I don't feel free. I understand the exhaustion and frustration many if not all face as caregivers but you don't want to have regrets that you didn't do enough because even when you did everything imaginable you still feel guilty. I'm overweight, with high blood pressure, high cholesterol and daily headaches. My doctor recently prescribed anti-depressants to cope with the devastating loss and lingering health problems I developed while working as a full time caregiver. I am no longer an active caregiver but speaking for my fellow caregivers in my support group, I can say that they desperately need help, mental, physical and financial but most aren't getting it.

Testimony of Jeanine Wong
Program Director, Caregiver Services
Hamilton- Madison House
Before the Committee on Civil Service and Labor
Jointly with the Committee on Aging and the Committee
On Finance
In relation to a comprehensive plan to address the needs of informal caregivers
(Int. No. 1081)

Thank you Committee members for this opportunity. I am Jeanine Wong, Program Director of Caregiver Services at Hamilton-Madison House. I am relatively new to this position; but the subject of caregiving is near and dear to me as I am an informal caregiver to my elderly mother. My mother, like many other immigrants, does not speak English, broken at best, nor understands the American culture.

I am fortunate to be a first generation English speaking Chinese American with the opportunities of higher education and additional assistance from my own family and siblings. While these may seem like small privileges, the gravity of them weighs heavily in instances of acquiring information (what type of affordable senior housing is there? How do I get Medicare/Medicaid for my parent? etc…) or the completing of forms (what type of information does my parent need to have or do I need to have? etc…). I know that not everyone is nearly as fortunate as I am, in the Asian/ Asian American community because these tasks for my parent were done prior to my knowledge or position at Caregiver Services. Through my short time working at Hamilton Madison House, I have become aware of these wonderful resources such as bilingual translators, information, assistance, counseling, respite, and supplemental that I believe would greatly benefit informal caregivers in similar situations. I believe it is pertinent that all caregivers, informal or not, be aware of such resources that the city can provide for the Asian community.

This study will do that. The purpose of this study is to alert informal Asian American caregivers of the resources that are at their disposal. With this knowledge, informal caregivers will be able to provide better care and be better informed. Caregiving is not just a side job, it is a full time position, formally or informally, that deserves the awareness of the assistance available out there.

Thank again for your time and I encourage you, Committee members, to develop the comprehensive plan that will address the needs of informal caregivers.

Jeanine Wong

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: Stephanie Mulcock
Address: 43-12 39 Ave
I represent: CIDADAO GLOBAL
Address:

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084 Res. No. ______

☒ in favor ☐ in opposition

Date: April 11, 2015

(PLEASE PRINT)

Name: Linda Oalican
Address: 406 W 40th St. Floor 3 NY, NY 10018
I represent: Filipino caregivers + domestic workers
Address: They reside in Queens Woodside, Elmhurst etc.

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: Nick Smith
Address:
I represent: DCA
Address:

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. 1084 Res. No. ____
☑ in favor ☐ in opposition

Date: 4/11/16

(PLEASE PRINT)

Name: Maritza Ortiz
Address: Long Island
I represent: New Immigrant Community
Address: Jackson Hts, Queens Empowermen

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084 1084 Res. No. ____
☒ in favor ☐ in opposition

Date: 4/11/16

(PLEASE PRINT)

Name: Chris Widelo
Address: 750 3rd Ave 32nd Fl
I represent: AARP
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: 4.11.16

(PLEASE PRINT)

Name: Robin Fenley, Assistant Commissioner,
Address: Bureau of HealthCare Connections
I represent: DFTA
Address: ____

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: 4.11.16

(PLEASE PRINT)

Name: Caryn Resnick, Deputy Commissioner,

Address: External Affairs

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: 4.11.16

(PLEASE PRINT)

Name: Donna Corrado, Commissioner

Address: DFTA

I represent:

Address:

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084+1081 Res. No. ______

☒ in favor ☐ in opposition

Date: 4-11-16

(PLEASE PRINT)

Name: Ilene Jokevine

Address: ~~34-46 71st, Jackson~~ Heights, NY 11372

I represent: National Domestic Workers Alliance

Address: 395 Hudson St. Fl4, New York, NY. 10014

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. 1084 Res. No. ______
☑ in favor ☐ in opposition

Date: 4/11/16

(PLEASE PRINT)

Name: Maggie Marron
Address: 305 Hicks St, Apt. 1, Brooklyn, NY
I represent: National Domestic Workers Alliance
Address: 395 Hudson St, 4th fl, NY, NY

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1081 Res. No. 2016
☑ in favor ☐ in opposition

Date: ______

(PLEASE PRINT)

Name: Bernadette Josephs
Address: 80-45 Winchester Blvd Queens Village NY 11427
I represent: Services Now For Adult Persons Inc.
Address:

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084 Res. No. ______
☑ in favor ☐ in opposition

Date: ______

(PLEASE PRINT)

Name: Linta Varghese
Address: ~~33~~ 495 Hudson st, NYC
I represent: Hand in Hand: Domestic Employers Network
Address: 333 Washington Av #2, Brooklyn 11205

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: 4-11-16

(PLEASE PRINT)

Name: JED A. Levine

Address: ~~360 Lexington Ave~~ / 112 W. 72

I represent: CaringKind

Address: 360 Lexington Ave

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1081 Res. No. ______

☑ in favor ☐ in opposition

Date: 4/11/16

(PLEASE PRINT)

Name: Helen Schaub

Address: 330 W. 42 St

I represent: 1199 SEIU

Address: Same

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1081 1084 Res. No. ______

☐ in favor ☐ in opposition

Date: 4/11/16

(PLEASE PRINT)

Name: Jed Levine

Address:

I represent: Caring Kind

Address:

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: 4/11/16

(PLEASE PRINT)

Name: Bobbie Sackman

Address: Live On NY

I represent:

Address: 49 W45St, ny 10036

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084 Res. No. ______

☐ in favor ☐ in opposition

Date: 4/9/16

(PLEASE PRINT)

Name: SYLVIA VOGELMAN

Address: 245 W 107th ST 6H, NY 10025

I represent: JEWS FOR RACIAL & ECONOMIC JUSTICE

Address: 330 SEVENTH AVE, NY

THE COUNCIL
THE CITY OF NEW YORK

Appearance Card

I intend to appear and speak on Int. No. 1084 Res. No. ______

☒ in favor ☐ in opposition

Date: 4/9/16

(PLEASE PRINT)

Name: Rachel McCullough

Address: 330 7th Ave. Suite 1901 New York NY 10001

I represent: Jews for Racial + Economic Justice

Address: "

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. 1084 Res. No. ______

☑ in favor ☐ in opposition

Date: 4/11/2016

(PLEASE PRINT)

Name: Sarah Leberstein 101 Cooper St. #6C NYC 10034

Address: 75 Maiden Lane Suite 601 NYC 10038

I represent: National Employment Law Project

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: Allison JULIEN

Address: 1633 Sterling Place

I represent: NDWA

Address: 395 Hudson Street

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: 4/11/16

(PLEASE PRINT)

Name: Molly Krakowski

Address: ______

I represent: JASA

Address: ______

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. 1081 + 1084 Res. No.

☒ in favor ☐ in opposition

Date: 4.11.16

(PLEASE PRINT)

Name: Carol Rodat

Address: 141 E. 56th NY, NY;

I represent: PHI

Address: 400 E. FORDHAM RD, BRONX NY

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. 1084 Res. No.

☒ in favor ☐ in opposition

Date:

(PLEASE PRINT)

Name: Lindsay Greene

Address: City Hall

I represent: Deputy Mayor Housing and Economic Development

Address: City Hall

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