



CARING ACROSS NEW YORK CITY

ENVISIONING A HOME CARE SYSTEM THAT MEETS THE NEEDS
OF HOME CARE WORKERS, SENIORS, PEOPLE WITH DISABILITIES
AND THEIR FAMILIES





ABOUT ALIGN

ALIGN's mission is to create good jobs, vibrant communities, and an accountable democracy for all New Yorkers. Our work unites worker, community, and other allies to build a more just and sustainable New York.

For more information visit www.alignny.org



ABOUT CARING ACROSS GENERATIONS

Caring Across Generations is a campaign for quality care and support, and a dignified quality of life for all Americans, across generations. The New York Care Council is building a coalition of community, worker, elder, faith-based, disability, policy and advocacy organizations and individuals committed to justice, dignity and high-quality care for both care givers and those receiving care.

Caring Across New York City

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Chayeinu; La Fuente; Linkage House; Left Labor Project; Make the Road New York; Mitchell-Lama Resident Coalition; New Lane Senior Center; New York Statewide Senior Action Council; New York City Chapter Alliance for Retired Americans; Pathways to Housing; Personal Touch Homecare Agency; PHI; Professional Staff Congress./ CUNY Retiree Chapter; Retail Action Project; 1199SEIU United Healthcare Workers East; United Food and Commercial Workers Local 2013; United Federation of Teachers Retiree Chapter; Upper Park Avenue Community Association site 5 & 6; and Unitarian Universalist Congregation at Shelter Rock. Special thanks to Akemi Nishida, Namrata Pradhan, Josefina Hernandez and Tyletha Samuels for your leadership in coordinating and moderating the focus groups; and to the disabled and elderly consumers of in home services and supports, domestic workers, homecare workers, and family care givers who participated in focus groups and interviews. By sharing your experiences you have enriched our survey findings immensely.

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The research project was a close collaboration between member organizations of the New York Care Council: ALIGN, Bend the Arc, Brown Community Development Corp., Domestic Workers United, the Greater New York Labor-Religion Coalition, Jews for Racial & Economic Justice, New York Statewide Senior Action Council, PHI, Professional Staff Congress/CUNY Retiree Chapter, and 1199SEIU United Healthcare Workers East.

Thanks to the National Employment Law Project, PHI and the National Domestic Workers Alliance for past research that informed this project.

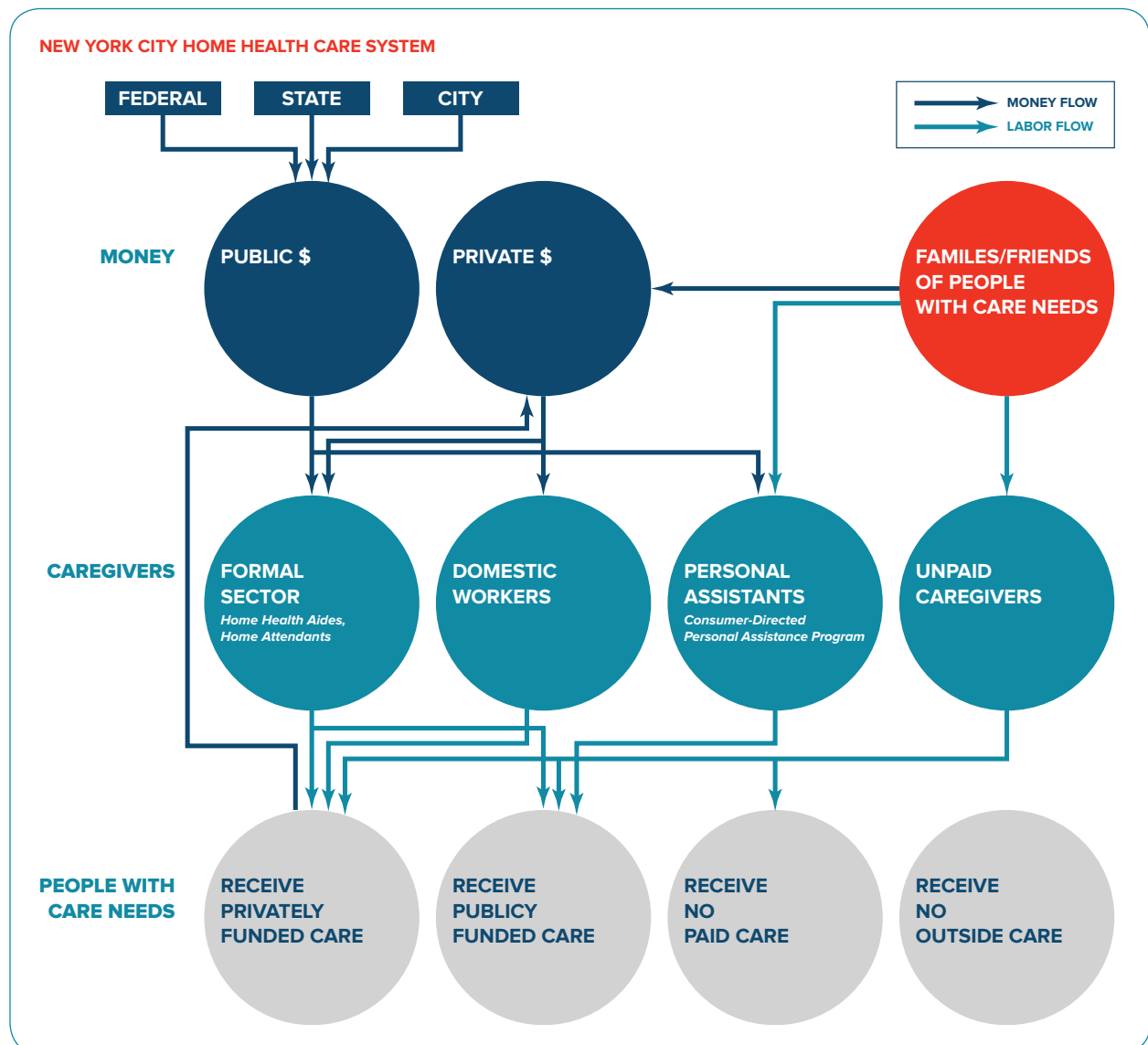
INTRODUCTION

Over one million New Yorkers interact with the home care system every day, their quality of life largely determined by how the system treats them. Paid and unpaid caregivers provide in-home services and supports to seniors and individuals with disabilities who need assistance with activities of daily living like bathing, dressing, and eating, and with instrumental activities of daily living like cooking and cleaning.

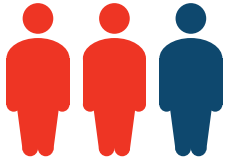
Demand for home care is growing as New York City’s Baby Boomers turn 65—one every eight seconds¹—and as life expectancy rises.² Two-thirds of people over the age of 65 will need

some form of long-term care at some point in their lives.³ Over 90 percent of aging New Yorkers would prefer that care to be community-based rather than institutional.⁴ With the 65 plus population projected to reach 1.4 million by 2030,⁵ close to one million New Yorkers could need home care in the next few of decades.

The home care system—which employs 155,000 formal sector home care workers⁶ and an increasing share of New York City’s 120,000 to 240,000 domestic workers⁷—will be the single biggest driver of employment in the city in the coming years. Certified home care workers (home health



aides and home attendants) are projected to grow faster than any other group of workers in the city between 2010 and 2020, seeing an almost 50 percent expansion, and adding over 76,000 jobs.⁸



2 in 3 seniors will need some type of long-term care

The home care system holds the potential to create thousands of good jobs for New Yorkers in need of employment and to honor the preferences of seniors to age in place and individuals with disabilities to live integrated within communities. However,

in order for the home care system to live up to its great promise, several systemic issues must be addressed.

Many senior and disabled individuals with care needs struggle to access quality home care. With increasing retirement insecurity,⁹ and rising costs of care, moderate-income individuals who do not qualify for Medicaid will face major challenges accessing the care they need.

Home care workers ensure that our elders and loved ones with disabilities receive needed care and support, but are often subjected to strenuous and even exploitative working conditions, and earn low wages and few benefits for their labor. An estimated one in five adult city residents provides some caregiving support for family, friends, or neighbors. Unpaid caregivers provide caregiving support to loved ones, many times at great personal cost, and receive little financial, emotional, and training support.¹⁰

Caring Across Generations is a national effort that seeks to build a home care industry that ensures dignity, respect, and a good quality of life for caregivers and people who receive care. The campaign seeks to create a home care system that will reliably and effectively meet the long-term care needs of the population for years to come, and provide family-sustaining jobs to millions of workers.

At the local level, the New York Care Council—a broad coalition of care providers, people who receive care, and community, labor, and policy advocacy organizations—launched the local chapter of Caring Across Generations at the June 2012 New York Care Congress. Over 500 New Yorkers, including members of labor and community organizations, faith leaders, and public officials,

attended the event. Since its launch, the New York Care Council has been growing and gaining support of the national Caring Across Generations policy platform: increase support for people who receive home care and their families, create home care jobs, improve home care job quality, improve home care training and establish career ladders for home care workers, and establish a pathway to citizenship for undocumented workers providing home care.

The Care Council is now working to formulate a local agenda. A strong history of organizing by worker organizations has secured significant gains for New York's home care workers, including the historic Domestic Workers Bill of Rights and a wage standard and overtime protections for formal sector home care workers. Disability rights and senior organizations have been advocating for more affordable and higher quality home care for decades. These efforts have laid the groundwork for further gains to be won for caregivers and people who receive care in New York City and State.

Committed to taking a ground-up approach to building its local agenda, the New York Care Council launched the Care Connections Survey Project in the fall of 2012.

Through more than 1,200 surveys, as well as focus groups and interviews, we uncovered



1 in 5 adult New Yorkers is a caregiver

aspects of the home care system that respondents believe are in greatest need of change, informed by the direct experiences of New Yorkers who are caregivers, people who receive care, and family providers/ arrangers of care.

Findings reveal that New Yorkers have a great deal at stake in the home care system—their financial security, health and safety, and dignity and respect. Building a home care system that works for caregivers and people who receive care will require innovative policy and organizing approaches, as well as a cultural project to address the classism, racism, nativism, sexism, heterosexism, ageism, and ableism at the root of the undervaluation and indignities that both caregivers and people who receive care experience within the home care system.

MAJOR SURVEY FINDINGS

Top 5 priorities of all New York City residents surveyed:

1. Raising **wages** of home care workers (86%)
2. Ensuring **health care** access for home care workers (58%)
3. Providing better quality **training** for home care workers (57%)
4. Providing **retirement security** to home care workers (48%)
5. Improving **monitoring of abuse/neglect** of people who receive home care (47%)

Top 5 priorities of New York City caregivers surveyed:

1. Raising **wages** of home care workers (90%)
2. Ensuring **health care** access for home care workers (67%)
3. Providing better quality **training** for home care workers (62%)
4. Providing **retirement security** to home care workers (58%)
5. Creating opportunities for **career advancement** for home care workers (52%)

Top 5 priorities of people who receive care in New York City surveyed:

1. Raising **wages** of home care workers (87%)
2. Providing better quality **training** for home care workers (57%)
3. Ensuring **health care** access for home care workers (53%)
4. Improving **monitoring of abuse/neglect** of people who receive home care (52%)
5. Improving home care **affordability** (49%)

Poverty Wages

62 percent of formal sector home care workers and **92 percent** of domestic workers surveyed reported that their annual household income is under \$25,000.

27 percent of formal sector home care workers and **38 percent** of domestic workers surveyed reported that their annual household income is under \$15,000.

Quality of Care Concerns

38 percent of people who receive care surveyed described the quality of their home care as “very poor,” “poor,” or “fair.”

Care Affordability Concerns

69 percent of survey respondents with unmet care needs cite inability to afford the care they need as the reason for not receiving required care.

Rising Demand for Home Care

51 percent of all survey respondents (median age of 57) anticipate that they or a loved one will need home care for the first time in the next ten years.

METHODOLOGY

The New York Care Council undertook the Care Connections Survey Project in order to develop a deeper understanding of the experiences and concerns of New Yorkers vis-à-vis the home care system, and to determine aspects of the system New Yorkers are most passionate about changing.

Surveys were implemented to gather information about aspects of the home care system New Yorkers believe are in greatest need of change, and surveys, focus groups, and interviews indicate the ways in which these concerns are informed by the experiences of New Yorkers.

THE SURVEY

The primary method of data collection for the project was a 28-question survey. The survey enabled the Care Council to gather a large amount of data in a relatively short period of time.

The survey instrument was crafted collaboratively by New York Care Council organizations, and included 21 fixed response and 7 free response questions about respondents' current and anticipated interaction with the home care system, priorities for change, and demographic characteristics such as age, gender, race, and household income. The survey instrument was translated into Spanish and Chinese.

In total, 1,217 surveys were collected by trained, paid survey collectors, at a variety of locations, including senior and community centers, places of worship, and at organizational meetings. Survey collectors were chosen from a variety of organizations in order to achieve stakeholder, geographic and demographic diversity.

We surveyed

1,217

New York City residents from across the five boroughs

We conducted focus groups and interviews with

32

New York City residents

CHARACTERISTICS OF THE SURVEY SAMPLE

Relationship to the Home Care System:

60 percent are caregivers, 20 percent are people who receive care and 20 percent are neither caregivers nor people who receive care.

Geography: Approximately one third (33 percent) of respondents reside in Brooklyn and Manhattan, respectively, 13 percent in the Bronx, 12 percent in Queens, and 9 percent in Staten Island.

Race: 23 percent white, 37 percent black, 38 percent Latino; 2 percent Asian

Gender: 73 percent female, 27 percent male

Household Income: 62 percent below \$25,000; 17 percent between \$25,000 and \$50,000; 21 percent above \$50,000

FOCUS GROUPS AND INTERVIEWS

Focus groups and interviews were conducted to delve into the reasons behind survey respondents' priorities for home care system change. Focus group and interview questionnaires were developed collaboratively by New York Care Council organizations, and conducted with help from community organizations like Make the Road New York and the Cornell Worker Institute. Focus groups/ interviews were conducted with six stakeholder groups, and 32 people, including formal sector home care workers such as home health aides and home attendants, domestic workers, unpaid/ family caregivers, people who receive publicly-funded home care, people who receive privately-funded home care, and people with disabilities under the age of 65 who receive home care.

PROJECT TIMELINE

December 2012

Survey instrument developed.

January 2013

Survey leader recruitment & training, survey collection begins.

April 2013

Survey collection complete; survey data input begins; focus group and interview questionnaire developed; focus group and interview recruitment.

May 2013

Survey data input complete; survey data analysis begins; focus groups and interviews conducted.

June 2013

Survey, focus group, and interview data analysis complete; survey project report drafted.

July 2013

Survey project report circulated to Care Council organizations for feedback; survey project report complete.

August 2013

Survey project report release.

STATEMENT OF LIMITATIONS

Findings in this report should be viewed as indicative of hypotheses that may need further quantification. Non-probability sampling techniques were employed for data collection, largely due to the hard-to-reach nature of the populations surveyed.



SURVEY PROJECT FINDINGS AND ANALYSIS

TOP PRIORITIES OF ALL SURVEY RESPONDENTS

Three of the top five priorities of all survey respondents—a group that includes New Yorkers who receive home care and caregivers, and New Yorkers who neither receive nor provide home care—deal directly with improving conditions for home care workers.

TOP PRIORITIES OF CAREGIVERS VS. PEOPLE WHO RECEIVE CARE

The side of the care relationship an individual occupies—whether she is a caregiver or an individual who receives care—shapes her priorities for change.

People who receive care, including individuals with disabilities, people who pay for care with Medicaid, and people who pay for care out-of-pocket gave “raising wages of home care workers” top priority. Second on their list was “improving monitoring of abuse/neglect of home care recipients,” followed by two objectives related to improving worker benefits, and finally, “increasing home care affordability,” an objective that was not on the top five list of caregivers.

Caregivers, including formal and informal sector care workers, and unpaid/family caregivers, had priorities similar to those of survey respondents overall. However, caregivers chose “Creating opportunities for career advancement for home care workers” above priorities like “Improving monitoring of abuse/neglect of home care recipients.”

TOP PRIORITIES OF PAID VS. UNPAID CAREGIVERS

Whether or not an in-home caregiver is providing paid care for a client or unpaid care for a friend or family member influences her priorities for change.

Formal and informal sector home care workers had the same top five concerns, which dealt with home care worker wages, working conditions, and training. However, a larger share of home health aides and home attendants (94%) than domestic workers (89%) were concerned about raising wages. Access to quality training was

more of a concern for domestic workers (71%) than formal sector care workers (59%).

Unpaid/family caregivers’ priorities differed from those of paid care workers. “Improving home care affordability” and “improving monitoring of abuse/neglect of home care recipients” were top priorities for unpaid/family caregivers, perhaps because many unpaid/family caregivers help to finance paid care for their loved ones, or would like to but lack the financial resources.

TOP PRIORITIES OF PEOPLE WITH DISABILITIES WHO RECEIVE CARE

People with disabilities who receive care were the only group for which “improving access to information about how to find and pay for home care” was a top 5 priority. People with disabilities who receive care are most likely to use the Consumer-Directed Personal Assistance Services program, in which consumers find and train their own caregivers. Focus group findings reveal that care recipients using consumer-directed services face challenges finding caregivers.

TOP PRIORITIES OF PEOPLE WHO RECEIVE PUBLICLY-FUNDED VS. PRIVATE-PAY CARE

The way in which a consumer’s care is financed—whether through a public program or with private funds—has a bearing on her priorities for change.

All five of the top priorities of people who receive care whose care was funded by Medicaid and other public programs such as the New York City Department for the Aging Expanded In-home Services for the Elderly Program were related to improving conditions for home care workers.

“Improving home care affordability” and “providing financial support (e.g. tax credits) to families caring for seniors/people with disabilities” were the second- and third-highest priorities, respectively, for private-pay consumers and their loved ones, with over 60% choosing these objectives. Neither of these objectives made the top five for people who receive publicly-funded care.

ENSURING THE FINANCIAL SECURITY OF CAREGIVERS AND PEOPLE WHO RECEIVE CARE

- 1** Raising Wages of Home Care Workers
- 2** Providing Retirement Security to Home Care Workers
- 3** Creating Opportunities for Career Advancement for Home Care Workers
- 4** Improving Home Care Affordability
- 5** Improving Access to Information About How to Find and Pay for Home Care
- 6** Providing Financial Support to Families Caring for Seniors/People with Disabilities

1

RAISING WAGES OF HOME HEALTH CARE WORKERS

All survey respondents, across various caregiver and care recipient sub-groups, chose **“raising wages of home care workers” as the objective they would most like to see the New York Care Council pursue.** Surveys showed that most home care workers earn poverty or near-poverty wages. Focus groups and interviews revealed that low wages earned by home care workers

made it difficult for them to provide for the needs of their families. People who receive home care who responded to the survey and participated in focus groups were well aware of the low wages home care workers earn, and there was broad support among people who receive care for increasing worker pay.

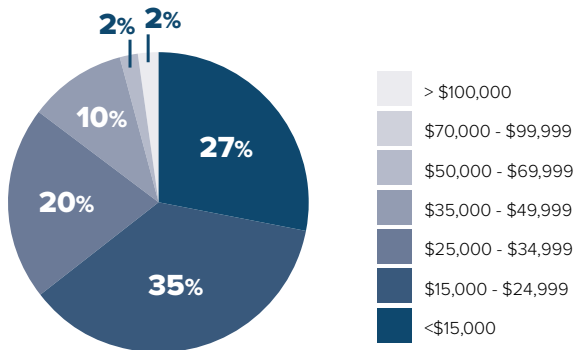
	OVERALL	All In-home Caregivers	Home Health Aides & Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients
“Raising wages of home care workers” a top 5 priority of the group:	○	○	○	○	○	○	○	○	○

94 PERCENT OF FORMAL SECTOR HOME CARE WORKERS CHOSE “RAISING WAGES OF HOME CARE WORKERS” AS A TOP PRIORITY.

Why raising wages is important to home health aides and home attendants:

62 percent of Home Health Aides and Home Attendants surveyed reported an annual household income under \$25,000.

FORMAL SECTOR HOME CARE WORKER ANNUAL INCOME



Type of Worker	Median Annual Wage
Home Health Aide, NYC	\$18,950
Home Attendant, NYC	\$21,480

Source: New York Department of Labor, 2011 data

Home Health Aides and Home Attendants report that they face difficulties making ends meet. Many home care workers are primary income earners for their families, and the low wages they earn as home care workers are inadequate to support their families. Workers report that recent agency cutbacks to work hours have made making ends meet more challenging than ever.

“You had to work a lot of hours, like 12 hours and I worked the 7 days, the salary was too low. It causes problems with the family...Wages have gone up over the last 15 years, but not by a lot.”

– Male, home attendant, age 55

“The salary is really little, especially now that they are cutting hours. My salary is the principal one for my household. You have to work a lot of hours to make ends meet. I used to have an apartment just around the block but I moved because it was just too much.”

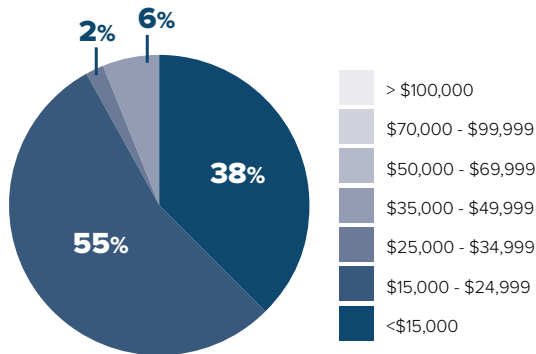
– Female, home attendant, age 44

89 PERCENT OF DOMESTIC WORKERS SURVEYED CHOSE “RAISING WAGES OF HOME CARE WORKERS” AS A TOP PRIORITY.

Why raising wages is important to domestic workers:

92 percent of domestic workers surveyed reported an annual household income under \$25,000.

DOMESTIC WORKER INCOME



Domestic workers report that they face difficulties making ends meet.

Eight of eight domestic workers that participated in our focus group were the primary earners for their families. Six out of eight had children, and 4 were helping to support extended family members with their salary.

“I have five children, two grandsons, I have brothers and sisters...I have to [provide for them, I have to do it...my husband was sick and he passed away last December [2012].”

– Female, domestic worker, age 52

I do my work well...and the person I care for is very satisfied with my work. It is very dignified work but it needs to be paid better.

– Female, domestic worker, age 42

Domestic workers report that they work long hours and do not receive overtime pay.

Sometimes we stay there for five days...and we don't know what's outside...You cannot leave the job. I get paid for every single hour I work, but I don't get overtime.

– Female, domestic worker, age 38

I earned \$300 in a week working 6, 7 days...I was on call 24 hours.

– Female, domestic worker, age 45

82 PERCENT OF UNPAID/FAMILY CAREGIVERS SURVEYED CHOSE “RAISING WAGES OF HOME CARE WORKERS” AS A TOP PRIORITY.

Why raising wages is important to unpaid/family caregivers:

Unpaid family caregivers, many of whom pay out-of-pocket for home care for a loved one, or would like to, expressed the need to pay workers a higher, fairer wage.

I felt very strongly that somebody working for me should at least be getting a living wage. ...I felt very strongly that I didn't want to be in that position of getting what I could, you know, that I wanted to be able to make sure that somebody was being paid in a fair way.

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

There seem to be many dedicated home workers who are underpaid, but would do anything for their clients.

– Female, unpaid caregiver, 41

The workers are by and large very good, but they often are not treated well by the people they take care of and are not paid enough.

– Female, unpaid caregiver, 62

87 PERCENT OF PEOPLE WHO RECEIVE CARE SURVEYED CHOSE “RAISING WAGES OF HOME CARE WORKERS” AS A TOP PRIORITY.

Why raising wages is important to people who receive care:

People who receive care expressed their desire to see home care workers earn higher, family-sustaining wages.

I think about the lady that I have now. She definitely should [be earning a higher wage]. She has to take care of her son. She struggles. She's a single parent. She's the one paying the bills. And she still has to go to social services to get help because she doesn't make enough.

– Female, home care recipient, age 54

Many do their work well but they are not happy because of the meager salary they receive. This should improve ... We need this service in New York.

– Female, home care recipient, age 79

People who receive care made the connection between worker wages and the quality of care they receive.

Low job quality is one of the major drivers of high turnover in the home care industry. According to PHI, turnover for home health aides in New York City is between 25 and 50 percent.³ High turnover rates negatively impact care continuity and quality, and impose hiring and training costs on the system.

I think that if home care workers received better salaries, they would provide better services.

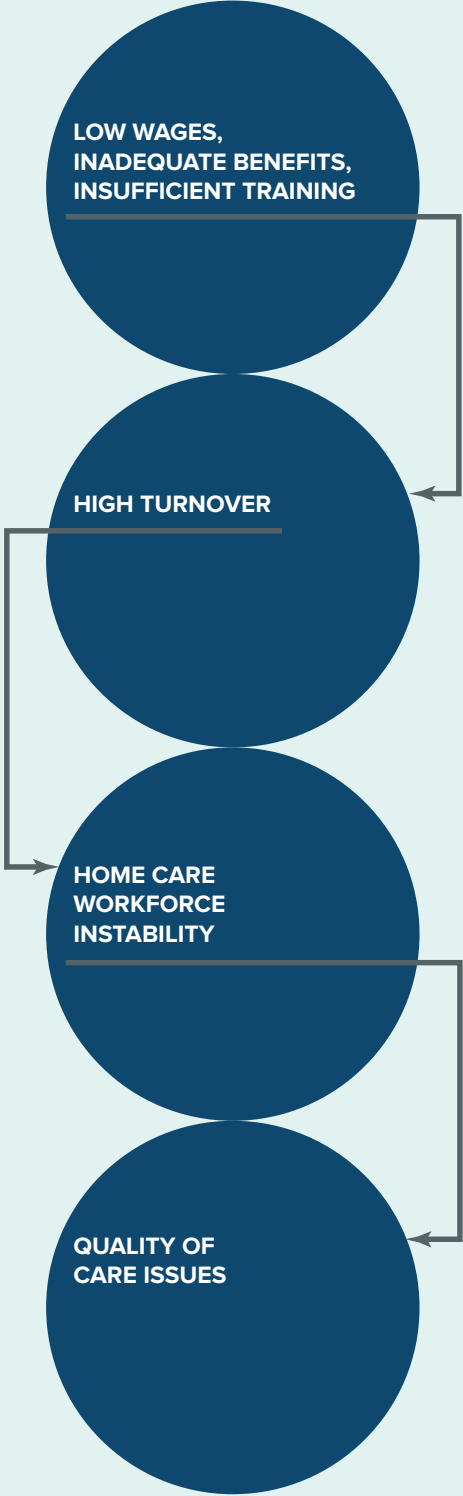
– Female, home care recipient, age 70

If home workers received better treatment and salaries, they would be more dedicated to their work.

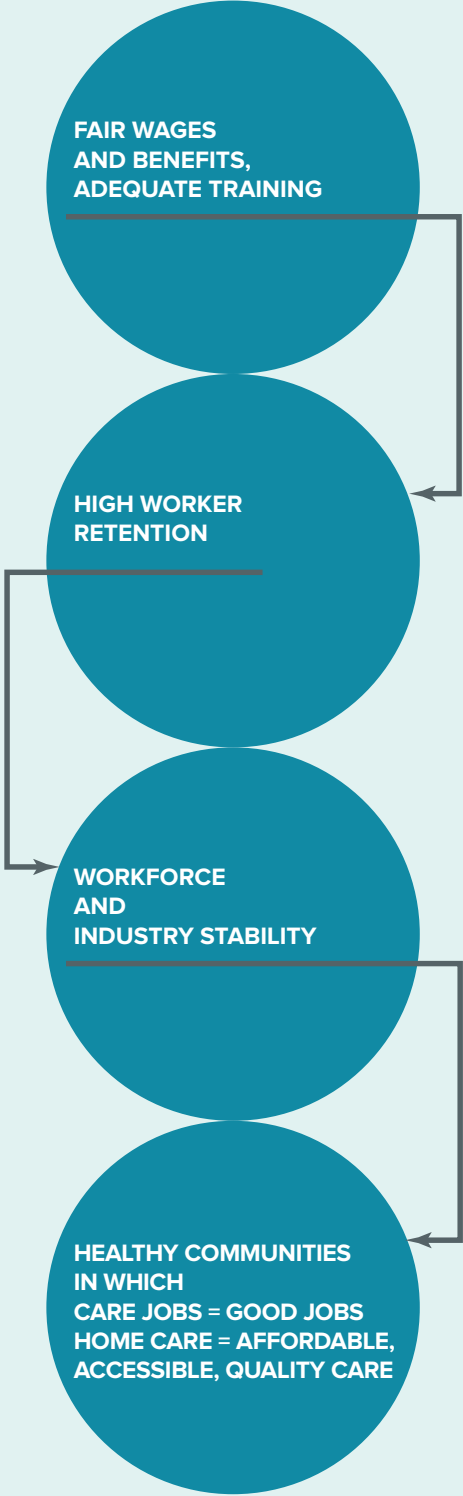
– Male, home care recipient, age 82

CONNECTING JOB AND CARE QUALITY

**NEGATIVE CONSEQUENCES
OF LOW JOB QUALITY
IN HOME CARE**



**POSITIVE EFFECTS
OF IMPROVING
HOME CARE QUALITY**



2

PROVIDING RETIREMENT SECURITY FOR HOME CARE WORKERS


Survey respondents overall, paid caregivers, and people with publicly-funded home care chose “providing retirement security for home care workers” as an objective they would like to see the New York Care Council pursue. A survey by the National Domestic Workers Alliance

revealed that only a small fraction of domestic workers receives retirement or pension benefits. The focus group with formal sector home care workers revealed that low wages earned by home care workers made it difficult for them to save for retirement.

	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/ Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Providing retirement security for home care workers” a top 5 priority of the group:	○	○	○	○				○	


67 PERCENT OF DOMESTIC WORKERS SURVEYED CHOSE “PROVIDING RETIREMENT SECURITY FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why improving retirement security is important to domestic workers:

 **Most domestic workers do not receive retirement and pension benefits, and are unable to save money for retirement.** According to a survey conducted by the National Domestic workers Alliance, just 2 percent of domestic workers receive any retirement or pension benefits. According to the same survey, only 23 percent of domestic workers were able to save any money in the last month.¹²

63 PERCENT OF FORMAL SECTOR HOME CARE WORKERS CHOSE “PROVIDING RETIREMENT SECURITY FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why improving retirement security is important to formal sector home care workers:

 **Low salaries of home care workers make saving enough for retirement a challenge.** As one focus group participant explains, non-union home care workers without pensions face difficulties retiring.

My salary has me super poor. When I worked my salary covered everything just fine, I had a good life. But then when I stopped working I am super poor. I am trying to see if I can find a way to go back to working.

- Female, former home health aide, age unknown

3

CREATING OPPORTUNITIES FOR CAREER ADVANCEMENT FOR HOME CARE WORKERS

Survey respondents overall and paid caregivers chose “creating opportunities for career advancement for home care workers” as an objective they would like to see the New York Care Council pursue. Wage data from the New York Department of Labor shows that, while the average experienced worker sees a significant

rise in income, for home health aides and home attendants, job experience does not translate into any real rise in income. The home care industry lacks clear career ladders. Domestic workers, many of whom are undocumented, lack access to formal sector career advancement opportunities.

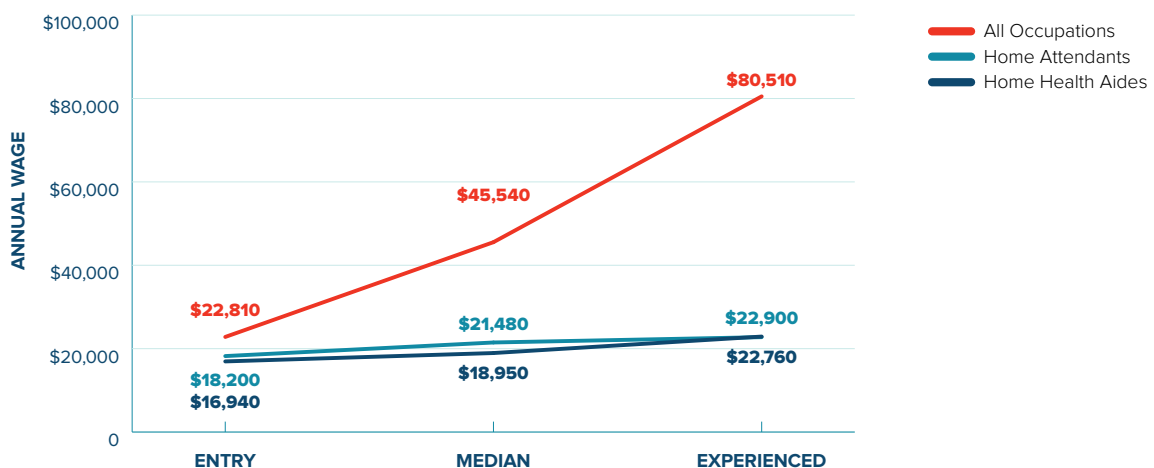
	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Creating opportunities for career advancement for home care workers” a top 5 priority of the group:	○	○	○						

58 PERCENT OF FORMAL SECTOR HOME CARE WORKERS CHOSE “CREATING OPPORTUNITIES FOR CAREER ADVANCEMENT FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why creating career advancement opportunities is important to formal sector home care workers:

While the average experienced worker sees a significant rise in income, for home care workers, job experience does not translate into any real rise in income.¹³

WAGES: HOME CARE WORKERS V. ALL WORKERS, NYC



Source: New York Department of Labor, May 2013



The home care industry lacks clear career ladders. According to the PHI, “Direct-care workers lack clearly articulated industry-recognized avenues for advancement...The state’s direct-care curriculum and training programs do not provide a simple understandable pathway

from personal care aide to home health aide, to certified nursing assistant.”¹⁴ The New York State Medicaid Redesign Team has plans to create an articulated pathway from Personal Care Aide to Home Health Aide to Certified Nurse Aide.¹⁵

56 PERCENT OF DOMESTIC WORKERS CHOSE “CREATING OPPORTUNITIES FOR CAREER ADVANCEMENT FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why creating career advancement opportunities is important to domestic workers:



Many domestic workers cannot access formal sector career advancement opportunities because of their immigration status. A large share of domestic workers in New York City are undocumented,¹⁶ which prevents them from seeking formal sector training and career advancement opportunities.



Domestic workers express keen interest in training certificates.

To be a babysitter for elderly people, I really know how to do...but we need...more [training]... if not, we are going to be in the same state we are [in] now...How to work with people with dementia and Alzheimer’s...these skills will be helpful...And if I develop more skills, I can earn more money.

– Female, domestic worker, age 52



NICIA HASSELL

Nicia is a domestic worker originally from the Dominican Republic. She has lived in New Jersey for the past three years, and is a full-time care giver for a senior who lives in Staten Island. She has worked at other kinds of jobs, but really loves what she does now. “The difference with this job is I love to take care of people. I do it with my grandmother; I do it with my children. I love to help other people,” says Nicia.

Nicia’s mother is also a home care worker. She works for an agency and receives training two to three times a year. They sometimes share stories about difficult situations at work and exchange ideas about how to do things. Nicia’s client has dementia, and it takes special skill and patience to work with her sometimes. Nicia’s mother has suffered back pain from lifting clients in the past. Nicia has had some training, including in CPR. “I really would like to have training for different situations,” she says. “Every year you could update your skills—that would be very good.” Her client is 93 years old and Nicia anticipates that her care needs could change. “If she cannot get up from the bed, we have to know how exactly we have to hold her and make sure we don’t cause any problem to her or to ourselves.”

Although her health is still relatively good, Nicia’s client still requires around-the-clock care. The schedule can be grueling, with Nicia staying in her client’s home sometimes for five days in a row without a full night’s sleep or being able to go home and spend time with her two teenage

daughters. She wishes this kind of work provided paid vacation and sick leave, but most of all, she would like to be able to afford health insurance. She keeps a close eye on her daughters’ health, even on the days when she’s parenting by phone. Her daughters have both had health problems and she pays for everything, including her older daughter’s anti-seizure medication, out-of-pocket.

Nicia also worries about the health and safety of seniors who are home alone and don’t have family or home care workers there for them. She would like to see more seniors and people with disabilities have access to home care services and supports. She believes that people ought to value the work of care workers a bit more. “It’s something very very serious when we’re taking care of somebody,” says Nicia. “I say that I take care of my client the way I take care of my grandmother. I do it with the love in my heart.”

“The difference with this job is I love to take care of people. I do it with my grandmother; I do it with my children. I love to help other people.”

4

IMPROVING HOME CARE AFFORDABILITY


People who pay out-of-pocket for care and unpaid/family caregivers chose “improving home care affordability” as an objective they would like to see the New York Care Council pursue. According to our survey, the high cost of home

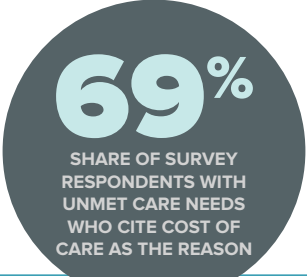
care prevents some New Yorkers from accessing the care they need, and private long-term care insurance may be inaccessible to people who want it.

	Overall	All In-home Caregivers	Home Health Aides & Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients
“Improving home care affordability” a top 5 priority of the group:					○	○			○


66 PERCENT OF PEOPLE WHO PAY OUT-OF-POCKET FOR CARE AND 51 PERCENT OF UNPAID CAREGIVERS (MANY OF WHOM HELP TO FUND PAID CARE FOR LOVED ONES) CHOSE “IMPROVING HOME CARE AFFORDABILITY” AS A TOP PRIORITY.


Why improving home care affordability is important to people who pay out-of-pocket for care:

 **People who receive care and their families face difficulties paying for home care.**



69%
SHARE OF SURVEY RESPONDENTS WITH UNMET CARE NEEDS WHO CITE COST OF CARE AS THE REASON

 **Home care is unaffordable for many people in New York City.** For people who have to pay out-of-pocket, the cost of care can be prohibitive. The median annual cost of a home health aide in Brooklyn is \$38,896.¹⁷ Paying out-of-pocket for a home health aide would deplete close to all of the earnings of a Brooklyn household with a median household income of \$44,593.¹⁸

 **Individuals with long-term care needs report that private long-term care insurance is not accessible to them.** Individuals who do not qualify for Medicaid, and who attempt to purchase private long-term care insurance, may not be able to afford the high cost, or may be rejected by insurance companies with exclusionary pre-existing conditions policies.

They wouldn’t insure [my husband]. This was years ago we tried. Whoever interviewed him decided he wasn’t insurable. What’s the point of insurance if the insurance doesn’t cover the people who need it?

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

5

IMPROVING ACCESS TO INFORMATION ABOUT HOW TO FIND AND PAY FOR HOME CARE


People with disabilities who receive home care chose “improving access to information about how to find and pay for home care” as an objective they would like to see the New York Care Council pursue. According to our survey, a large share of people with disabilities have unmet care needs. Since people with disabilities

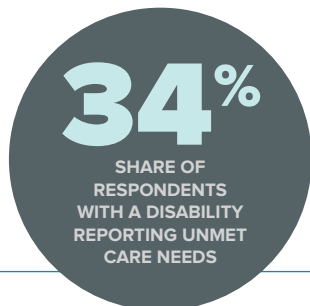
who receive care are more likely than people without physical disabilities that receive care to use consumer-directed home care services that require the consumer to recruit and train a home care worker, access to information about finding care is especially important to them.


	Overall	All In-home Caregivers	Home Health Aides & Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients
“Improving access to information about how to find and pay for home care” a top 5 priority of the group:							○		

45 PERCENT OF PEOPLE WITH DISABILITIES WHO RECEIVE HOME CARE CHOSE “IMPROVING ACCESS TO INFORMATION ABOUT HOW TO FIND AND PAY FOR HOME CARE” AS A TOP PRIORITY.

Why improving access to information about finding and paying for care is important to people who receive home care:

 A significant share of individuals with disabilities report that they are not able to access services and supports they need.



 People with disabilities who receive care report that networks are extremely important in helping to find care. Because individuals with disabilities often have unique care needs, they are more likely to be enrolled in the Consumer-Directed Personal Assistance Services program, which gives care recipients worker recruitment and training responsibilities. Finding care workers can be challenging, so networks are important.

[A friend] has tried to help me to crowd-source for care...I think having a network of people, even if you are across boroughs, definitely helps.

– Female, home care recipient, age 28

6

PROVIDING FINANCIAL SUPPORT TO FAMILIES CARING FOR SENIORS/PEOPLE WITH DISABILITIES

People who pay out-of-pocket for care and their families chose “providing financial support to families caring for seniors/people with disabilities” as an objective they would like to see the New York Care Council pursue. Interviews with families

providing care support and helping to pay for loved ones’ home care reveal that providing and subsidizing the home care for loved ones strains family budgets and takes a physical and emotional toll on family caregivers.

	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Providing financial support to families caring for seniors/people with disabilities” a top 5 priority of the group:									○

60 PERCENT OF PEOPLE WHO PAY OUT-OF-POCKET FOR CARE CHOSE “PROVIDING FINANCIAL SUPPORT TO FAMILIES CARING FOR SENIORS/PEOPLE WITH DISABILITIES” AS A TOP PRIORITY.

Why providing financial support to families helping to provide or pay for loved ones’ home care is important to people who pay out-of-pocket for care:

Providing unpaid home care for loved ones is costly and may force family caregivers to forego paid work. For low-income workers, many of whom do not get any paid or family leave, providing home care for a loved one can be especially financially burdensome.

Caring for our elderly family members can be a hardship on a family as a whole. Much like child care, home care for seniors can be a barrier to employment and a heavy financial expense to families who are already struggling to make ends meet.

– Male, unpaid caregiver and funder of paid care for loved one, age 35

To care for your parents is a privilege but...it is very difficult to do so while working outside the home.

– Female, unpaid caregiver for parent, age 50

Helping to fund paid home care puts tremendous strain on family budgets.

Well, I’ve been paying out of pocket. And my financial advisor told me we’re going to go bankrupt if I continued to do this. And, he said within two years you’re outta cash, you’re outta money.

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

Family caregivers report that there is a great physical and emotional toll that comes with caring for a loved one.

It has been physically and emotionally taxing in a way I did not expect...Being responsible for somebody...especially where it's a role reversal. When it's degenerative...all you do is wait for the next change that will make things indescribably worse. And so, you're at work, but you're worried about the person at home... Being a caregiver impacts everything...in your life...even at the times you're not there.

– Male, unpaid caregiver for parent, age 30 - 45

There are days I feel... very happy that I've been able to contribute...to somebody else's life. But most of the time I'm overwhelmed, exhausted, scared, and incredibly sad. That's really what I am most of the time.

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

Family caregivers express appreciation for the care services provided by care workers, who give them respite and peace of mind.

I'm lucky: we have the resources to hire the aides. But what if I didn't? What if I was the person who could never be more than an arm's reach from my husband...every day and night? I would never sleep...you, know, I could not do it.

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

We need to be able to go to work. Having aides lets us do that without worrying about my dad.

– Female, arranger of care for her father, age 36

PROTECTING THE HEALTH AND SAFETY OF CAREGIVERS AND PEOPLE WHO RECEIVE CARE

- 1** Ensuring Health Care Access for Home Care Workers
- 2** Improving Monitoring of Abuse/Neglect of People Who Receive Home Care
- 3** Providing Better Quality Training for Home Care Workers

1

ENSURING HEALTH CARE ACCESS FOR HOME CARE WORKERS

All survey respondents, across various caregiver and care recipient sub-groups, chose “ensuring health care access for home care workers” as an objective they would like to see the New York Care Council pursue. Focus groups revealed that home care workers face significant risks

of work-related injury and illness, which makes health care access especially important. Non-union home care workers who do not qualify for Medicaid are unlikely to have health insurance, and most domestic workers are uninsured.

	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Ensuring health care access for home care workers” a top 5 priority of the group:	○	○	○	○	○	○	○	○	○

72 PERCENT OF FORMAL SECTOR CAREGIVERS SURVEYED CHOSE “ENSURING HEALTH CARE ACCESS FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why health care access is important to home care workers:

Workers report that they are vulnerable to work-related injury/ illness and abuse.

We get exposed to different circumstances... Sometimes it is an environment where you contract an illness and the worker can get sick. ...I had a case of a woman who was 240 pounds and was partially paralyzed. I had to use a lot of force, a lot of effort.

– Male, home attendant, age 55

I worked with a woman who had diabetes. ...People with the condition put the used needles in a plastic container...[my client] would just throw them out. I got pricked twice...

– Female, home attendant, age 44

Many formal sector home care workers are uninsured. In New York City, unionized home health aides and home attendants meeting monthly work hour requirements have access to health insurance, but non-union home care workers who do not qualify for Medicaid are unlikely to have health insurance.¹⁹

73 PERCENT OF DOMESTIC WORKERS SURVEYED CHOSE “ENSURING HEALTH CARE ACCESS FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why health care access is important to domestic workers:



Most domestic workers are uninsured. According to a survey conducted by the National Domestic Workers Alliance, only about one-third (35%) have health insurance, and just 4% of domestic workers have employer-provided health insurance.

2

IMPROVING MONITORING OF ABUSE/NEGLECT OF PEOPLE WHO RECEIVE HOME CARE

Survey respondents overall, publicly-funded home care recipients, home care recipients with disabilities, and unpaid/family caregivers chose “improving monitoring of abuse/neglect of home

care recipients” as an objective they would like to see the New York Care Council pursue.

Focus groups reveal that people who receive care experience neglect.

	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Improving monitoring of abuse/neglect of home care recipients” a top 5 priority of the group:	○				○	○	○	○	

52 PERCENT OF PEOPLE WHO RECEIVE HOME CARE CHOSE “IMPROVING MONITORING OF ABUSE/NEGLECT OF HOME CARE RECIPIENTS” AS A TOP PRIORITY.

Why monitoring abuse and neglect is important to people who receive home care:

Elder abuse is a serious problem in New York. While home care workers are involved in some cases, family members are the primary perpetrators. A recent report by the New York City Department for the Aging found that one in seven seniors in New York has suffered some form—financial, physical and sexual, emotional—of abuse or neglect since turning 60. The same study found that just 1.19 percent of elder abuse case in New York City involved a home care worker.²⁰


People who receive care report that they experience neglect.

Sometimes the workers are not very responsible: they leave their patients alone, don't finish their hours and arrive late.

– Male, age 60

47 PERCENT OF UNPAID/FAMILY CAREGIVERS CHOSE “IMPROVING MONITORING OF ABUSE/NEGLECT OF HOME CARE RECIPIENTS” AS A TOP PRIORITY.

Why monitoring abuse and neglect is important to unpaid/family caregivers:

 **Many unpaid caregivers also fund paid home care for their loved ones, and want to ensure their safety.** 28 percent of family caregivers surveyed care for a loved one who also receives paid care.



PARK MCARTHUR

Park McArthur is a 28 year old artist living in New York City. She is currently working and studying with a number of art institutions, including the Whitney Museum of American Art. Park was born with an unclassified form of limb girdle muscular dystrophy. Because of her condition, she needs some assistance with things like getting out of bed and into her wheelchair, getting dressed, showering and cooking. Growing up, Park's family provided all of this assistance, although she needed much less assistance when she was younger. Park's condition is degenerative, which means she'll need more assistance as she ages.

When she was 21, she started to live on her own. Friends provided her with a lot of support and caregiving. "In a lot of ways it's really nice... because it's a trusting relationship and I feel like...I do have a lot of open communication," says Park.

Park has also used paid caregivers from time to time, mostly finding people through friends, acquaintances and other graduate students. Park currently shares an apartment with her sister, who was born with the same condition, and another roommate. Park explains, "Although this is not a form of direct payment, currently, one of my roommate's rent is subsidized, because she helps my sister and me with daily living needs."

She recognizes that she may require more care as her condition worsens over time. As a disability justice activist, she emphasizes the importance

of building strong relationships between care givers and those who receive care services and supports. "Everyone is different with unique needs, and consumer-directed services are one way to take this reality into account. From dietary needs, to lifting techniques, disabled people can and should be able to articulate their desires when receiving assistance. But we as disabled people also need guidelines and best practices about how to be good consumers and employers because these skills are not self-evident, and we need to share what we learn about how to be responsible, accountable employers."

Overall, Park stresses the importance of building a supportive community of friends and caregivers. "This kind of care and assistance means everything to me. It is the only way I am able to live the life I want to live, to live where I want to live, participating in communities and activities that are life-affirming."

Overall, Park stresses the importance of building a supportive community of friends and caregivers.

3

PROVIDING BETTER QUALITY TRAINING FOR HOME CARE WORKERS

All survey respondents, across various caregiver and care recipient sub-groups, chose “providing better quality training for home care workers” as an objective they would like to see the New York Care Council pursue. Surveys show that a large proportion of people who receive care are not satisfied with the quality of the care they receive. Lack of adequate training is one perceived cause of sub-par service quality. For people with

disabilities who receive care, “better quality” training means a larger role for care recipients with unique needs in the training of care workers to meet those unique needs. In focus groups, caregivers report that training is inadequate to meet the demands of their jobs. Lack of proper training in skill areas like infection control and proper transferring techniques can put workers at risk of illness and injury.

	Overall	All In-home Caregivers	Home Health Aides and Home Attendants	Domestic Workers	Unpaid/Family Caregivers	All Home Care Recipients	Home Care Recipients with Disabilities	Publicly-Funded Home Care Recipients	Private-Pay Home Care Recipients and Families
“Providing better quality training for home care workers” a top 5 priority of the group:	○	○	○	○	○	○	○	○	○

62 PERCENT OF CAREGIVERS CHOSE “PROVIDING BETTER QUALITY TRAINING FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why improving the quality of home care worker training is important to caregivers:

Home care workers report receiving inadequate training to meet the demands of their jobs. According to PHI, “Entry-level training is inadequate to prepare workers for home care clients with complex conditions, including Alzheimer’s and other forms of dementia.”²¹ Lack of proper training in infection control can put workers at risk of contracting diseases, and without proper training in transferring techniques, workers’ risk of back injury increases.

We work with very difficult people that demand many things that we are not prepared to accomplish... agencies only care about the person receiving the service and not for those that provide it.

– Female, home health aide, age 43

[Agencies] do not provide good training.

– Female, home health aide, age 39

We have to do jobs that we do not have training for.

– Female, home health aide, age 47

57 PERCENT OF PEOPLE WHO RECEIVE HOME CARE CHOSE “PROVIDING BETTER QUALITY TRAINING FOR HOME CARE WORKERS” AS A TOP PRIORITY.

Why improving the quality of home care worker training is important to people who receive home care:

A large share of people who receive home care report that the quality of care they receive is not good.

People [who] carry out these jobs, although well-intentioned, need better training.

- Female, living with a disability, age 58

38%

SHARE OF RESPONDENTS DESCRIBING THE QUALITY OF THEIR HOME CARE TO BE “VERY POOR,” “POOR,” OR “FAIR”

People with disabilities who receive care feel that they need more of a role in shaping the services and supports they receive.

That was a big fear...I don't want to have a home attendant come into my house and say this is the standard of care, and every day we have to meet this standard. That would freak me out...With the consumer-directed, I have my voice. The whole point of home care is...we have our voice and independence.

- Female, home care recipient, age 31

I can't transfer independently...my issue is that people either hold on too tight or too loosely...and depending on if you don't do whichever one I tell you, you're going to make me fall... [B]ecause they're trained in a certain way and they're so fearful for their jobs and fearful of you falling, they kinda just don't listen, and I'm just like, “no, you have to listen to me, you know what I mean? ...You have to listen because you're going to end up hurting yourself and the other person.

- Female, home care recipient, age 28

ENSURING THAT IN-HOME CAREGIVERS AND PEOPLE WHO RECEIVE CARE ARE TREATED WITH DIGNITY & RESPECT

Focus groups and interviews reveal the need to strengthen relationships between caregivers and people who receive care, making them less transactional and more cooperative, and the need to address broader socio-cultural issues of classism, racism, nativism, sexism, heterosexism, ageism, and ableism at the root of mistreatment and indignities suffered by both caregivers and people who receive care.



**All people have the right to
dignity in old age, as well as
dignity at work.**

– Female, age 65

1

ENSURING THAT HOME CARE WORKERS ARE TREATED WITH DIGNITY AND RESPECT

In focus groups, care workers reported that they face various kinds of abuse and indignities in the workplace. Paid home care workers in New York City are overwhelmingly female, of color, and largely immigrant women.²² Mistreatment is often rooted in classism, racism, nativism, sexism, and heterosexism.

Workers report feeling undervalued and disrespected in the workplace.

Several home care workers use words like “servant” and “slave” to describe the way clients seem to perceive them.

[The clients] treat us like we are disposable. Like a napkin, to use and throw away.

– Female, domestic worker, age 52

It is very difficult to work with elder folks who do not respect their workers...

– Male, home health aide, age 24

The patients think we are servants.

– Female, home health aide, age 29

It is a very difficult job at times because there are patients who think the home care workers are slaves.

– Female, home attendant, age 47

Home care workers report that they experience various forms of abuse—physical, verbal, and sexual.

Home care workers report that clients verbally abuse them, using racial epithets and derisive language when addressing them.

I had [my client] throw a glass on my face. It was real glass. Very wealthy people...it's like they don't care...they just throw the thing like that. I had bruises.

– Female, domestic worker, age 50

Because I'm Asian, [my clients] called me “Chinito.”

– Female, domestic worker, age 50

If I got anything wrong, [my client] would call me “stupid.”

– Female, home attendant, age 44

I had one [client] tell me that he liked my p---y and I pretended like I didn't understand a word...

– Female, home health aide, age 59

Home care workers report cases of clients and their families breaching the boundaries of the job description.

Some family members...think that because there is a home attendant that they have... someone to care for all of them.

– Female, home health aide, age 55

I would go with [my client] to the restaurants, and he would say that I could not say anything about being a home attendant because I was to pretend to be his girlfriend.

– Female, home health aide, age 55

2

ENSURING THAT PEOPLE WHO RECEIVE HOME CARE ARE TREATED WITH DIGNITY AND RESPECT

In focus groups and interviews, people who receive home care reported that they experience misrecognition and disrespect rooted in broader socio-cultural issues of ageism and ableism.

People who receive care report feeling disrespected by home care workers. Individuals with disabilities report that they feel infantilized by home care workers.

The infantilization is always an undercurrent.

– Female, home care recipient, age 31

I definitely agree with the infantilization...I am 28 years old...I think sometimes it doesn't register with [my home attendants]...that you can be disabled and...have your own preferences...they think...you can't be autonomous.

– Female, home care recipient, age 28

Many [home care workers] have a lack of respect for the elderly.

– Female, home care recipient, age 72

People who receive home care and family caregivers express a preference for in-home versus institutional care.

Quality humane care is more likely to be found in a home setting than in an institution.

– Female, unpaid caregiver for a loved one, age 61

I'm determined that he will not leave home, that he will not go into an institution. When he went into an institution it was beyond horrible. It was horrible for him, horrible for me, horrible. ...I'm absolutely determined that there's nothing we can't do at home.

– Female, unpaid caregiver and funder of paid care for loved one, age 50+

People who receive care and a former caregiver say that there is a need for relationship-building in order to cultivate mutual respect.

They are relationships with boundaries and they are relationships that come with forms of exchange that are monetary. But, what makes both a good care receiver and a good caregiver is...to be always feeling there are two people in the situation...to imagine the other things that construct someone's life...it's not just these hours when we're together.

– Female, home care recipient, age 28

There should be more respect between the patient and the worker.

– Female, former home health aide and current home care recipient, age 81



PAMELA HILL AND NORMA VALDEZ

Pamela Hill graduated college in 1997 and started working with kids, teaching pre-K through 6th grade mostly. Then she got sick. In 2004, she was diagnosed with Multiple Sclerosis (M.S.), a chronic disease that affects the nerve cells in the brain and spinal cord to communicate with each other effectively. At first she was worried that she would be put in a nursing home as her condition worsened. “I didn’t like that,” said Pamela. “I like to fly—be independent.”

Pamela now uses a wheelchair and has been receiving care from Cooperative Home Care Associates since 2009. Norma Valdez is a home health aide who cares for Pamela in her home in the Bronx, primarily on the weekends. “She respects me, and I love her just the way she is,” says Norma.

Originally from El Salvador, Norma knew from the time she was a little girl that she wanted to help people. “I see it in her eyes when she’s happy, when she’s sad, when she’s hyper, when she’s thinking,” says Norma. “I know her.” Norma helps Pamela get through tremors and doesn’t let them hinder her. But knowing how to treat her medical conditions is only one part of their relationship. According to Pamela, “You get to know your aid and your aid gets to know who you are—and it’s like a family. Norma is the type of the person that’s very observant. She watches everything and it’s like her heart just knows when you’re not having a good day, when you are having a good day.”

“I like that she’s committed, and I like that she values me as human being—I’m not just a number.”

Pamela likes to keep busy. She moves a lot and exercises, which helps slow the progression of her disease. She also participates in Artists on Wheels, a program and non-profit space that encourages wheelchair-bound people in the arts. Painting is Pamela’s favorite, and her aids help her get out her paint brushes and art supplies. Pamela has also traveled quite a bit in the last year, participating in the Miss Wheelchair competition. She won the title of Miss Wheelchair New York last year, and is competing this year for Miss Wheelchair Northeast. “I like that she’s doing Miss Wheelchair, and I hope she wins, just like she did the first time,” says Norma. “I know she can do it--she has the power.”

Pamela appreciates the support she receives from home care aids. “They encourage me. If I want to go out and do something I think I can’t, the first thing they say is ‘don’t doubt yourself—you can do anything you want to do.’” When asked what she likes most about working with Norma, Pamela says, “I like that she’s committed, and I like that she values me as human being—I’m not just a number.”

ANTICIPATING HOME CARE NEEDS

Demand for home care is rising as New York City's Baby Boomers turn 65 and as life expectancy rises.

ANTICIPATING HOME CARE NEEDS



If we have access to [home care], we won't fear old age.

– Female, anticipates needing home care in the next 10 years, 65



Over half of all survey respondents anticipate that either they or a loved one will need home care for the first time in the next ten years.

51%



A majority of survey respondents above the age of 65 anticipate needing home care for the first time in the next ten years.

58%



More than one-third of survey respondents above the age of 65 anticipate that a loved one will need home care for the first time in the next ten years.

35%



MELBA ADAMS

Melba is 73 years old and lives in Clinton Hill, Brooklyn. She was in a car accident a number of years ago and injured her leg. As her condition worsened, she decided to take early retirement from her job as a teacher, but she keeps busy volunteering. When asked how the accident changed her life, she says, “I don’t even think about my accident now, because it’s been a while. But I use a walker now. I was promoted from a cane to a walker.”

Melba has found herself relying on friends and neighbors more and more. She says, “I’m doing the best I can with the housework, but I can’t vacuum anymore. I need help going to the store and to the post office. I don’t go out alone anymore—not even to walk a block—because I have trouble getting around and I don’t feel safe.”

Ideally, Melba would like to receive home care. She says, “Before he died, my neighbor used to have a lady who would come to take care of him. She used to pick up things from the pharmacy for me if she was going for him.” She almost applied for services recently, but when the woman taking applications told her how much it would cost, she was discouraged. “I told her never mind—I can’t afford that,” recalls Melba.

Melba uses Access-a-Ride services for her doctors’ appointments and has also looked into getting a motorized chair. “I would like to get information on where I can go or call to get assistance,” she says. She wishes that there were meetings where home care workers, Access-a-Ride and ambulatory services people, and those who need care could just sit down and talk about the issues. “I lost a lot of my mobility, but I still have my voice,” says Melba.

“I’m doing the best I can with the housework, but I can’t vacuum anymore. I need help going to the store and to the post office. I don’t go out alone anymore—not even to walk a block—because I have trouble getting around and I don’t feel safe.”

STRATEGIES FOR BUILDING A BETTER HOME CARE SYSTEM

STRATEGIES FOR BUILDING A BETTER HOME CARE SYSTEM

Surveys, focus groups, and interviews point to aspects of the home care system that New Yorkers believe are in greatest need of change. This section presents promising strategies for building a home care system that ensures the financial security, health and safety, and dignity and respect of caregivers and people who receive care.

ENSURING THE FINANCIAL SECURITY OF IN-HOME CAREGIVERS AND PEOPLE WHO RECEIVE CARE

1 Raising Wages of Home Care Workers

Unions and worker collectives are perhaps the best vehicles through which home care workers can increase their wages. Low-wage service workers who belong to unions earn, on average, 20 percent more than their non-union counterparts.²³ Unions like 1199SEIU have organized over 75,000 home care workers in New York City, and have won contracts that include health care, education and pension benefits, paid time off, and raises. 1199SEIU recently helped to establish legal wage standards for home health aides and home attendants. A set of domestic worker collectives belonging to the National Domestic Workers Alliance worked in coalition with ally groups to pass the Domestic Workers Bill of Rights in 2010, a state-level bill that secured minimum wage protections for domestic workers.²⁴

Home care worker cooperatives, companies where home care workers own and operate the business and surplus value goes to workers rather than to administration and shareholders, can serve to improve compensation for workers while keeping the cost of care relatively low. The New York City-based Cooperative Home Care Associates, the United States' largest worker-owned cooperative, employs over 2,000 home care workers, about half of which are worker-owners.²⁵

Laws that link business licensure to wage and hour law compliance may help to curb wage theft, which is rampant in the home care industry.²⁶ In 2010, Make the Road New York led an effort that saw passage of the Wage Theft Prevention Act, which increased the unpaid wages workers can recover (from 25% to 100%), increased protections against employer retaliation, and requires that employers provide written pay notices to workers.²⁷ New York could build on the Wage Theft Prevention Act by passing a law, similar to Chicago's wage theft ordinance,²⁸ that would link business licensure to wage and hour law compliance, and could strip the licenses of home care agencies violating wage and hour law.

Increased enforcement of wage and hour laws, by the Department of Labor and the Department of Health, would ensure that home care workers receive the pay to which they are legally entitled. The Department of Health and the Department of Labor could work together to educate the industry about wage and hour laws like the recently passed Home Care Wage Parity Law,²⁹ and to respond more aggressively to claims of wage and hour violations.

2 Providing Retirement Security to Home Care Workers

Unions offer retirement security to members. Service workers are 25 percent more likely than their non-union counterparts to have a pension.³⁰

Publicly-sponsored retirement plans can provide home care workers with retirement security. New York City Personal Retirement Accounts (NYC PRAs) were launched in 2011. NYC PRAs pool employee and employer retirement contributions into pension accounts managed by the Bureau of Asset Management in the New York City Comptroller's Office, and the accounts are insured by the federal Pension Benefit Guaranty Corporation. The new pension plan guarantees a matching contribution by employers and accounts are fully portable across different employers.³¹

A combined 5 percent contribution (2.5 percent salary contribution by both the employer and employer) from a worker earning \$25,000 at age 25 would produce a monthly annuity of over \$560 at retirement, supplementing social security income and increasing retirement income by over 33 percent.³²

3 Creating Opportunities for Career Advancement for Home Care Workers

Establishing an Advanced Aide position as the next rung above home health aide, establishes a career ladder for formal sector home care workers. Advanced aides would receive training in skills like medication dispensation and would have an official role on care coordination teams, previously the reserve of doctors and nurses.³³ In New York, PHI and 1199SEIU have been working to create an advanced aide position.

Providing training certificates for domestic workers in skills like infection control and cardiopulmonary resuscitation would help domestic workers to build essential skills, improve marketability, possibly increase compensation, and initiate potentially ongoing relationships with training institutions.

Access to a path to citizenship for undocumented workers would allow many domestic workers access to previously inaccessible formal sector training programs and career advancement opportunities. A large share of domestic workers in New York City is undocumented.³⁴ The current national movement towards comprehensive immigration reform could bring undocumented care workers out of sometimes exploitative working conditions by providing a pathway to citizenship.

4 Improving Home Care Affordability

The Expanded In-Home Services for the Elderly Program (EISEP) provides in-home services and supports and care coordination services to New York City seniors age 60 years and older with long-term care needs. EISEP offers free or heavily-subsidized care to many low-income, non-Medicaid-eligible senior New

ACCESS TO HOME CARE PROVIDER BY INCOME LEVEL

TYPE OF HOME CARE PROVIDER	LEVEL OF ACCESS
● Home Health Aides/Home Attendants	● High
● Domestic Workers	● Medium
● Unpaid/Family Caregivers	○ Low



LOW-INCOME NEW YORKERS

with home care needs are likely to have access to Medicaid-covered home health aide and home attendant services unless they are undocumented. They have a low level of access to the in-home services of domestic workers due to inability to pay out-of-pocket for care. Low-income New Yorkers with home care needs may have access to family care, but low-income families are very unlikely to 1) be able to forgo paid work-time to provide unpaid care; 2) have paid leave; and 3) have flexible work hours.



MIDDLE-INCOME NEW YORKERS

with home care needs have no guaranteed access to any type of home care provider. They may qualify for Medicaid-covered home care if they spend down assets, and they may qualify for limited home care services subsidized by the New York City Department for the Aging. They may be able to afford to pay out-of-pocket for a certified home care or domestic worker for a limited duration of time. Middle-income New Yorkers with home care needs may have access to family care, but middle-income families may not 1) be able to forgo paid work-time to provide unpaid care; 2) have paid leave; and 3) have flexible work hours.



HIGH-INCOME NEW YORKERS

with home care needs have guaranteed access to certified and domestic workers, because they can afford to pay for whatever care they need. They may have access to family care, since high-income family members are likely to receive paid leave, although they may have long/inflexible work hours.



Yorkers.³⁵ In New York City, over 4,000 seniors receive services through EISEP, however, many seniors are on waiting lists for EISEP services because the program is underfunded.³⁶ EISEP in New York City is funded by federal Older Americans Act (OAA) money.³⁷ In the past, New York City has chosen to supplement OAA funds, but it is not currently doing so.

A public long-term care insurance program

would provide a more affordable home care funding option than private long-term care insurance for seniors who are not eligible for Medicaid. New Yorkers would pay into the system for a period of time prior to being granted access to the benefit. Hawaii is currently considering such a policy.³⁸

5 Improving Access to Information about How to Find and Pay for Home Care

New York Connects, a locally-based care coordination service that offers “one stop access to free, objective and comprehensive information and assistance on long-term services and supports,”³⁹ would provide New York City residents with direct access to advice on long-term care services. New York City is one of a handful of localities that has not implemented the New York Connects program, opting instead to provide care information through the 311 system instead.

A more robust home care worker registry that provides not only information about number of years of experience and whether a worker is certified, which New York’s Home Care Registry currently provides, but also, information about the special skills or training of workers, and training opportunities for consumers and workers, could help to address both care quality and job quality issues.⁴⁰

A web portal connecting responsible employers with domestic workers and home care workers would create a space for a “high-road model” of home care provision, fostering quality jobs and quality care. The web portal could serve as a repository of information for care workers and people who receive care, with template contracts, worker and employer rights

guides, and other resources. Hand in Hand: The Domestic Employers Association is a national network of employers of nannies, housecleaners and home attendants with a chapter in New York City. Hand in Hand is planning to launch a new website this year that will include resources for domestic employers, such as a sample contract and a living wage calculator.

6 Providing Financial Support to Families Caring for Seniors/People with Disabilities

Providing paid family leave supports unpaid caregivers who currently need to take time off from work to care for seriously ill loved ones. The Family Leave Insurance Act, which would use small employee payroll deductions (by some estimates, less than 60 cents per week) to provide workers with up to 12 weeks of paid leave, is pending in the New York State Legislature.⁴¹ California, New Jersey, and Rhode Island currently have statewide paid family leave laws. Washington State passed a paid family leave law, but implementation has been postponed.

Refundable tax credits may help to defray the financial burden placed on families supporting loved ones with long-term care needs.

PROTECTING THE HEALTH AND SAFETY OF CAREGIVERS AND PEOPLE WHO RECEIVE CARE

1 Ensuring Health Care Access for Home Care Workers

Unions often negotiate health care benefits for members. Unionized service sector workers are approximately 19 percent more likely than their non-union counterparts to have health insurance.⁴²

Health Care Cooperatives offer a way for home care workers, including those who are undocumented, to access health care at an affordable rate. In Los Angeles, the Restaurant Opportunities Center (ROC) partnered with local health providers to launch a health care cooperative, “ROC-MD,” that provides low-cost

primary medical, dental, and mental health care to members, including those who are undocumented, for a \$25 monthly fee.

Educating Care Workers about the Affordable Care Act and the New York State Health Benefit Exchange

can facilitate home care worker access to health care. The Affordable Care Act extends Medicaid coverage to an additional 500,000 uninsured people in New York City, potentially including many home care workers.⁴³ Home care workers exceeding the income threshold for Medicaid may be eligible for subsidized health insurance through the New York State Health Benefit Exchange.⁴⁴

2 Improving Monitoring of Abuse/ Neglect of Home Care Recipients

Mandatory reporting of abuse and neglect of seniors and individuals with disabilities can help stop abuse and neglect. New York is one of only three states in the United States that does not have a mandatory reporting requirement for elder abuse.⁴⁵ Only a small fraction of elder abuse cases is reported.⁴⁶ Mandatory reporting requires individuals to report cases of elder abuse and neglect or face fines or jail time.

Elder abuse prevention services provide a means through which seniors can report both physical and financial abuse to trained staff. The 2014 budget of the New York City Department for the Aging eliminates elder abuse prevention services. The City Council provided \$800,000 in 2013 to fund elder abuse prevention services, which served about 1,000 seniors.⁴⁷

3 Providing Better Quality Training for Home Care Workers

Scaling up the most effective training programs—those that offer specialty skills (e.g. dementia care) training and use an adult learner-centered pedagogical approach—would better equip home care workers to meet the care needs of their clients.⁴⁸

Making home care certification testing more language-accessible would allow trainees to take tests in their native language. While the city currently makes training available in multiple languages, it does not do the same for tests. PHI is involved with a City Council-funded project to translate tests in to seven languages.⁴⁹

Creating specialty content areas that address the needs of unique populations will help to meet the individual needs of people who receive care. PHI and the Alzheimer’s Association have developed training modules in areas like dementia care and disability care.⁵⁰

ENSURING THAT IN-HOME CAREGIVERS AND PEOPLE WHO RECEIVE CARE ARE TREATED WITH DIGNITY & RESPECT

Eldercare dialogues and codes of care create opportunities for caregivers and those who receive care to build relationships and codify a promise of mutual respect between care worker and client. In New York City, domestic worker organizations affiliated with the National Domestic Workers Alliance, including Domestic Workers United, Adhikaar, and Damayan, Jews for Racial & Economic Justice, and B’nai Jeshurun, have collaborated to conduct a series of eldercare dialogues in 2012 and 2013, which entail domestic workers and domestic worker employers building deep community, learning about shared values and interests, and taking action to ensure quality jobs and quality care for all. The organizations involved look forward to piloting an innovative training program that serves workers, consumers, and their families.

A popular education strategy can help to bring about a reevaluation of care work and combat forms of oppression that shape the experiences of in-home caregivers and people who receive care. The New York Care Council has a storytelling project, giving voice to people directly impacted by the home care system. The aim is to share care stories through workshops, earned and social media, and popular culture like film and television. The New York Care Council also meets regularly and engages home care workers, seniors, individuals with disabilities, and other stakeholders via workshops and trainings aimed at breaking down cultural barriers, understanding power, and building relationships.

CONCLUSIONS

With each passing day, the home care system—which brings together paid and unpaid care workers and people with care needs—becomes a more significant presence in New York City. Demand for home care is surging as Baby Boomers reach their 60s, life expectancy increases, and individuals with long-term care needs opt for home-based rather than institutional care. Scores of New Yorkers are joining the ranks of the city's hundreds of thousands of care providers—as home health aides and home attendants, domestic workers, and unpaid family caregivers.

A well-functioning home care system can help to grow New York City's middle class, and make the city as supportive of seniors and people with disabilities as it strives to be. However, currently, many home care workers in New York City do not receive livable wages and benefits, and many individuals with care needs and their families struggle to find and pay for high-quality home care.

Whether or not the expanding home care industry will be an engine of good jobs, lifting care workers and their families into the middle class, a provider of accessible, quality care that enables people with long-term care needs to remain in their homes, and whether the industry and state and local policies will be supportive of families who provide and/or finance care for their loved ones remains to be seen. How well the home care system serves the needs of all New

Yorkers in the coming years will be shaped by how effectively communities organize and how comprehensively policymakers respond.

The Care Connections Survey Project has given voice to New Yorkers' concerns and experiences vis-à-vis the home care system. Caring Across New York City reveals aspects of the home care system that New Yorkers are most passionate about changing. Overwhelming support across stakeholder groups—of both providers and consumers of home care services—for objectives such as raising the wages of home care workers⁵¹ indicates that New Yorkers are able to transcend a zero-sum calculus that regards gains for care workers and gains for people receiving care as mutually exclusive. The report also offers some broad strategies that could transform the home care system into one that ensures the financial security, health and safety, and dignity and respect of both caregivers and people with care needs.

Rollout of the Affordable Care Act and Medicaid Redesign has placed the home care system in a state of flux, and created a critical moment for political engagement to steer systemic change. In the coming months, the New York Care Council will use the findings and strategies for change presented in Caring Across New York City to advance a policy and organizing agenda aimed at building the just and inclusive home care system that New Yorkers envision. Please join us.

APPENDIX

APPENDIX A

The Policy and Organizing Priorities of Survey Respondents

OBJECTIVE	SHARE OF GROUP PRIORITIZING OBJECTIVE								
	Overall (%) (n = 1101)	All In-home Caregivers (%) (n = 750)	Home Health Aides & Home Attendants (%) (n = 530)	Domestic Workers (%) (n = 66)	Unpaid/Family Caregivers (%) (n = 154)	All Home Care Recipients* (%) (n = 230)	Home Care Recipients with Disabilities (%) (n = 86)	Publicly-Funded Home Care Recipients (%) (n = 110)	Private-Pay Home Care Recipients** (%) (n = 99)
Raising wages of home care workers	86	90	94	89	82	87	91	93	82
Ensuring health care access for home care workers	58	67	72	73	56	53	49	55	54
Providing better quality training for home care workers	57	62	59	71	62	57	53	60	57
Providing retirement security to home care workers	48	58	63	67	45	38	37	45	31
Improving monitoring of abuse/neglect of home care recipients	47	41	40	27	47	52	67	64	46
Improving home care affordability	43	33	25	29	51	49	42	35	66
Creating opportunities for career advancement for home care workers	40	52	58	56	38	33	24	28	30
Providing financial support (e.g. tax credits) to families caring for seniors/people with disabilities	35	30	23	38	41	39	30	25	60
Improving access to information about how to find and pay for home care	32	23	19	19	34	41	45	38	41
Increasing access to unpaid/family caregiver support groups	24	20	17	25	24	29	37	34	18
Increasing consumer direction in worker training	19	19	22	24	12	22	21	26	14
Other	6	5	5	5	6	5	5	5	5

* Includes people who receive unpaid care

** Includes family of private-pay care recipients

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