**Department for the Aging**

# TESTIMONY

Presented by

**Donna M. Corrado, PhD**
**Commissioner**

on

**Oversight: Supporting Unpaid Caregivers**

before the

**New York City Council**
**Committee on Aging**

on

**Wednesday, November 29, 2017**
**10:00 A.M.**

at

**Council Chambers, City Hall**
**New York, NY 10007**

Good morning, Chairperson Chin and members of the Aging Committee. 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; Robin Fenley, Assistant Commissioner for the Bureau of HealthCare Connections; and Joshua Sidis, Senior Advisor for the Mayor's Office of Operations. Thank you for the opportunity to discuss supporting unpaid, informal caregivers.

Millions of people throughout the U.S. are informal caregivers. More than 44 million individuals provide care for both biological and chosen family members who are chronically ill, disabled, or aged.[1] These caregivers assist with running errands, paying bills, preparing meals, picking up and administering medications, helping with activities of daily living such as bathing, 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.[3] Nationally, 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 in the U.S. spends 41 hours or more per week providing care.[5] The economic value of these informal, unpaid caregivers is an estimated $470 billion per year.[6] Women comprise 66 percent of caregivers in the U.S. and are 2.5 times more likely than non-caregivers to live in poverty, coping with the combined pressures of caring for a loved one, their need for income, reliance on public assistance, and fewer employment-related benefits.[7]

In addition, 2.7 million grandparents in the U.S. serve as the primary caregiver for their grandchildren.[8] More than half of these grandparents—55 percent—have been serving as primary

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[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] Family Caregiver Alliance – National Center on Caregiving. Women and Caregiving: Facts and Figures.

[8] Ellis and Simmons. Coresident Grandparents and Their Grandchildren: 2012. Population Characteristics, October 2014.

caregivers for three years or more, and 38 percent have been doing so for five years or more.[9] One-fifth, or 22 percent, of grandparent caregivers are living below the federal poverty line, while 10 percent among the general population of individuals ages 50 and older are below the federal poverty line.[10] In New York City, about 66,000 grandparents are raising grandchildren under 18 years old.[11]

## 2017 SURVEY OF INFORMAL CAREGIVERS

As you know, DFTA was charged in August of 2016 with conducting a citywide survey of caregivers in an effort to gain a better understanding of the needs of these 1.3 million+ caregivers in New York City. This 2017 Survey of Informal Caregivers came together through the collaborative efforts of governmental entities – DFTA, the Mayor's Office of Operations, the Administration for Children's Services, the Mayor's Office for People with Disabilities, and the New York State Office for People with Developmental Disabilities. DFTA and the Mayor's Office of Operations formed a coalition of various experts from social service agencies throughout this process to help shape and implement the survey. In addition, the survey included AARP caregivers, who were not known to be affiliated with the government or provider network. Westat, a nationally known social service research company, conducted the survey and provided preliminary analyses. Survey results were based on the participation of more than 2,000 New York City caregivers. DFTA has been working closely with the Mayor's Office of Operations in analyzing and mining the survey data, which will guide the City's response to the growing need of caregivers. The Mayor's Office of Operations will delve into the survey findings in their testimony.

## DFTA 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 $8 million for FY '18, DFTA's ten caregiver programs have served more than 6,200 individuals throughout the City in FY '17, providing information about caregiving, discussing the associated stressors and

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[9] Livingston. Pew Research Center. At Grandmother's House We Stay, September 4, 2013.

[10] Id.

[11] 2010 U.S. Census.

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.

As you know, the current funding level of $8 million for caregiver programs includes an additional $4 million baselined in FY '18 to support caregivers. This was a major investment by the Administration, which doubles DFTA's existing Federal allocation for caregiver services. As a result of this enhanced funding, based on FY '17 service levels, DFTA anticipates that by FY '19:

- Double the number of caregivers receiving individual home care and group adult day care respite will be served;
- Triple the number of caregivers utilizing overnight or other respite for their care receivers will benefit from these services; and
- The number of caregivers receiving supplemental services will increase by 25 percent.

This new caregiver funding is intended to provide support to the caregiver and/or care receiver with the creative flexibility they need to access services, while ensuring the quality of care by the selected service provider. Existing caregiver program contracts will be amended to include this funding.

To clarify outreach efforts and illustrate how individuals are identified as caregivers, and subsequently connected to services, DFTA's caregiver programs canvass neighborhoods with flyers advertising their services, they write articles on caregiving for local papers, they appear on radio or television to discuss caregiving issues, and they conduct free information sessions on a variety of caregiving-related topics, such as memory loss, alternative residential options, and community resources.

Caregiver assistance is also available through DFTA's Caregiver Resource Center. In FY '17, more than 3,500 individuals received information and referrals regarding residential alternatives, long term care services and supports, and appropriate community services. Case consultation is provided to other professionals seeking services as well.

The Caregiver Resource Center, like many other DFTA units, conducts outreach by way of participation on panels or other public speaking opportunities, providing yet another avenue for caregiver self-recognition. Increasingly, websites, Facebook, and Twitter are being utilized by providers to attract the younger caregiver. Calling 311 will also put caregivers or inquirers in touch with DFTA's Caregiver Resource Center or NY Connects, which will connect callers to resources in their borough.

In addition, the Caregiver Resource Center provides contract oversight to its ten contracted caregiver programs, ensuring compliance with meeting the expectations of the National Family Caregiver Support Program and its DFTA contract. These programs meet monthly for administrative updates, case discussion and problem-solving, information sharing on pertinent events, as well as presentations by experts who provide additional resources for caregiver clients.

### 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 FY '17, there were more than 500 grandparent caregivers served. Through the GRC, more than 2,600 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 Action Plan for Neighborhood Safety or MAP. The GRC received $472,000 since FY '15 for DFTA Community Advocates to work with residents at 15 New York City Housing Authority developments, and provide resources and services to grandparent caregivers. Through the initiative, grandparent and relative caregivers have received grandparenting education, community safety trainings, intergenerational programming, and peer support on raising children.

## CONCLUSION

Thank you again for this opportunity to provide testimony on supporting unpaid, informal caregivers. We have only begun to scratch the surface in understanding the breadth of the needs of informal caregivers, and how best to respond, while preserving the uniqueness of each individual's approach to caring. Local Law 97 provided the opportunity to address this. If there is one overarching takeaway from the 2017 Survey of Informal Caregivers in New York City, it is the similarity of need, regardless of who is being cared for. Following testimony by the Mayor's Office of Operations, I, along with my DFTA colleagues, will be pleased to answer any questions you may have.

THE CITY OF NEW YORK
OFFICE OF THE MAYOR
NEW YORK, N.Y. 10007

# Testimony of Joshua Sidis on Supporting Unpaid Caregivers
# In front of the Committee on Aging
# November 29th, 2017

Good morning Chairwoman Chin and members of the Committee on Aging. I am Joshua Sidis, Senior Advisor for the Mayor's Office of Operations. I've been closely involved in the creation and delivery of the Survey of Unpaid Caregivers in New York City, as well as the report on unpaid caregiving released this Fall. I, alongside Commissioner Corrado, am also coordinating the effort to draft the recommendations and the comprehensive plan required by Local Law 97, which will be delivered to the City Council by the end of the year. Thank you for the opportunity to speak today about the efforts taken to understand the unpaid caregiving community in New York City, and for your attention to this important issue.

The Mayor's Office of Operations first became involved in this initiative because the office has experience guiding complex projects on tight timelines. As Ops quickly learned, the effort also became a natural fit as it involved an intense amount of inter-agency work and external coordination. As many in this room can attest, this project was a tremendous effort that included strategic development, research, and expertise. While a year goes by quickly, those involved in this work accomplished a lot in a short amount of time.

The survey was created using insights from DFTA, the Mayor's Office for Economic Opportunity (NYC Opportunity), the Administration for Children's Services (ACS), the Mayor's Office for People with Disabilities (MOPD), the New York State Office for People with Developmental Disabilities

(OPWDD), and AARP, as well as external stakeholders and providers. The City partnered with Westat, an external research firm, to develop a survey that met high standards for statistical analysis. The surveys were available in several languages: Russian, Korean, Chinese, and Spanish, and large-text options were available for the vision impaired.

The study divided the unpaid caregiver population into three primary groups. Each was provided a similar but specialized survey tailored to their experiences. The three groups were: 1) Adults caring for family members over the age of 60, including those with Alzheimer's disease or other dementia; 2) grandparents or other relatives who are the primary caregivers of children under 18, and; 3) adults caring for individuals with disabilities between the ages of 19 and 59. Alzheimer's and other dementia was not broken out into its own group because although these are unique problems, many of the services and funding sources for helping these populations overlap significantly with others for older adults. Additionally, it is difficult to distinctly disaggregate people with dementia from those without. Caregivers of people with memory loss may not always acknowledge that the person they care for has a problem, attributing their behavior to old age rather than an illness.

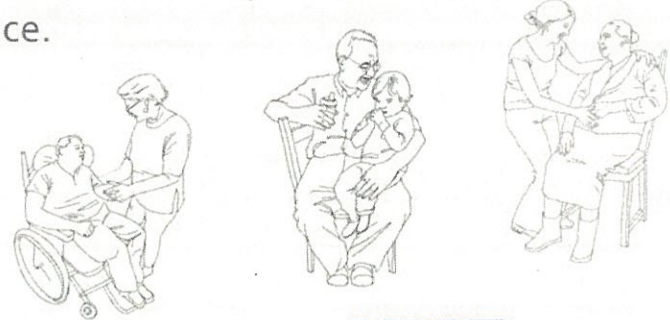
NYC Opportunity and Westat conducted the survey after first collecting ample demographic information about all caregiver groups to assure there was a diverse field of participants. After identifying groups of participants—including but not limited to ACS foster parents, participants in DFTA programs, and AARP members who identified themselves as caregivers—random samples of each sub-set were taken and surveys were mailed or emailed to caregivers. The survey also noted a point of contact at each agency for questions or help. Due to the nature of the survey audience, most surveys were mailed via standard post. Each survey was designed to take about 30 minutes to complete, and response rates ranged from 10 – 30 percent for each group. These response rates are noteworthy given survey's depth, distribution methods, and length.

All surveys addressed two primary questions: 1) to what extent are unpaid caregivers able to obtain the services they need, and 2) what barriers do unpaid caregivers continue to face when they do obtain those services. The study also collected demographic information about the unpaid caregiver population and their burden. Information about areas of need were recorded, as well.

Ops has prepared a presentation that summarizes the survey's topline results, which will be discussed now. The deck will be entered into the record for this hearing.

# Unpaid Caregivers Hearing
## 11/29/17

A survey of unpaid caregivers in New York City, about who they are, what they need, and the barriers they face.



NYC Mayor's Office of Operations

Confidential Draft – For Discussion Purposes Only

- There are between **900,000– 1.3M** caregivers in New York City.

- This survey reached out to approximately 18,000 New Yorkers who identified as unpaid caregivers. The survey found:
  - Most caregivers are **women** over the age of **50**.
  - More than half of caregivers provide more than **30 hours of care per week**.
  - Two of the most-prevalent barriers to obtaining services were **lack of knowledge regarding available services** and **income/financial limitations.**
  - At least one-third of each caregiver group **struggled financially.**

# Profile of Family Caregivers of Adults with Disabilities

- Most respondents were women.
- Most respondents were non-white (60%).
- Most respondents were older than 50.
- English is the primary language for most respondents (93%).

| **Caregiver demographic** | **Caregivers of Adults with Disabilities (All)** |
|---|---|
| **Gender** | |
| Male | 16 |
| Female | 84 |
| **Age** | |
| Under 50 years | 32 |
| 50 to 59 years | 34 |
| 60 years or older | 34 |
| **Race/ethnicity** | |
| Hispanic | 22 |
| White non-Hispanic | 40 |
| Black non-Hispanic | 23 |
| Other non-Hispanic | 15 |
| **Primary language[1]** | |
| English | 93 |
| Spanish | 8 |
| Other languages | * |

*Less than 1 percent.

[1] Respondents could report more than one response.

NOTE: Percentages may not sum to 100 because of rounding or multiple responses. Percentages are based on estimated numbers of caregivers responding to the questions reported in this table: (510).

SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Profile of Kinship Caregivers

- ACS Kinship Foster Caregivers and caregivers served by DFTA's Grandparent Resource Center (GRC) were surveyed.
- A majority of both groups were women, African American, and list English as their primary language.
- DFTA caregivers are more likely to be 65+.

| Caregiver demographic | GRC kinship caregivers (%) | ACS kinship caregivers (%) |
|---|---|---|
| **Gender** | | |
| Male | 14 | 10 |
| Female | 86 | 90 |
| **Age** | | |
| Under 65 years | 37 | 74 |
| 65 or above years | 63 | 26 |
| **Race/ethnicity**[1] | | |
| Hispanic | 24 | 30 |
| Black non-Hispanic | 61 | 57 |
| Other non-Hispanic[1] | 15 | 13 |
| **Primary language**[2] | | |
| English | 84 | 94 |
| Spanish | 18 | 14 |
| Other languages | 5 | * |

* Less than 1 percent.

[1] This category includes White non-Hispanic caregivers, due to small numbers of caregivers in this race/ethnic group.

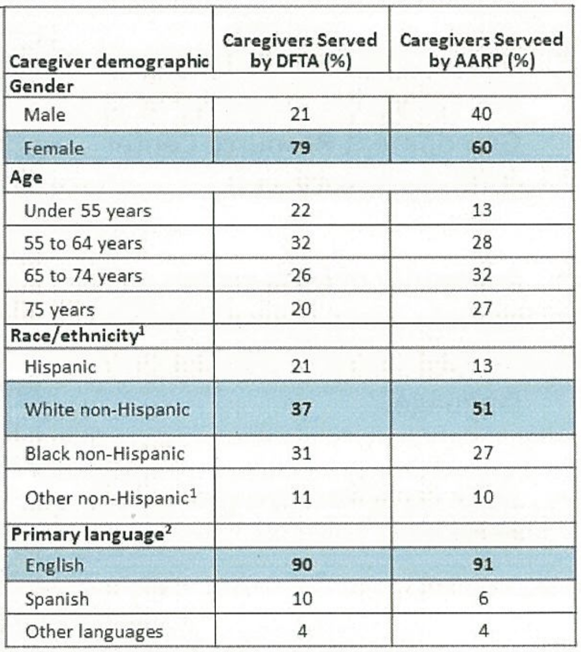
[2] Respondents could report more than one response.

NOTE: Percentages may not sum to 100 because of rounding or multiple responses. Percentages are based on estimated numbers of caregivers responding to the questions reported in this table: (GRC=890; ACS=1,600).

SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.

# Profile of Caregivers of Older Adults

- Respondents were mostly women (60% for AARP, 79% for DFTA).
- For DFTA respondents: 37% were white non-Hispanic, 31% were black, 21% were Hispanic.
- Most list English as their primary language.
- DFTA caregivers were more likely to be over 65.



| Caregiver demographic | Caregivers Served by DFTA (%) | Caregivers Servced by AARP (%) |
|---|---|---|
| **Gender** | | |
| Male | 21 | 40 |
| Female | **79** | **60** |
| **Age** | | |
| Under 55 years | 22 | 13 |
| 55 to 64 years | 32 | 28 |
| 65 to 74 years | 26 | 32 |
| 75 years | 20 | 27 |
| **Race/ethnicity**[1] | | |
| Hispanic | 21 | 13 |
| White non-Hispanic | **37** | **51** |
| Black non-Hispanic | 31 | 27 |
| Other non-Hispanic[1] | 11 | 10 |
| **Primary language**[2] | | |
| English | **90** | **91** |
| Spanish | 10 | 6 |
| Other languages | 4 | 4 |

[1] Respondents could report more than one response.

NOTE: Percentages may not sum to 100 because of rounding. Percentages are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).

SOURCE: Family Caregiving for Older Adults: 2017.

# Caregivers of Adults with Disabilities – Caregiver Service Needs

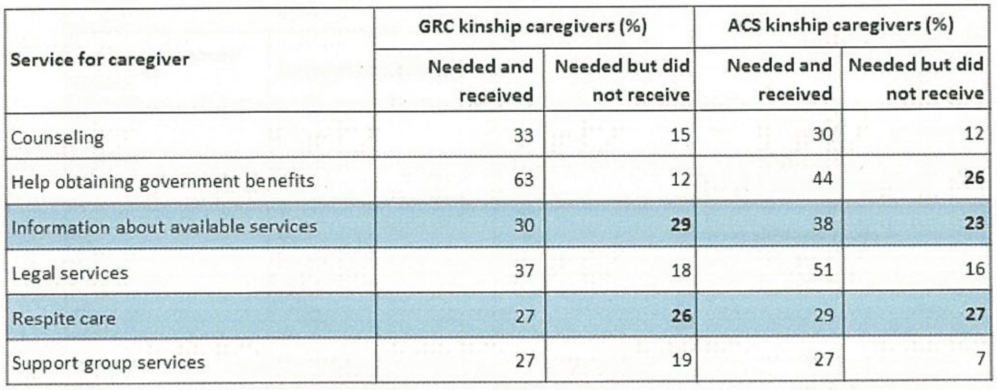
- Caregivers reported needing but not receiving **Respite care** and **Information about available services**.

| Service for caregiver | Percent | |
|---|---|---|
| | Needed and received | Needed but did not receive |
| Counseling | 18 | 34 |
| Help obtaining government benefits | 38 | 22 |
| Information about available services | 35 | 30 |
| Legal services | 21 | 32 |
| Respite care | 27 | 35 |
| Support group services | 12 | 31 |

NOTE: Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (510).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kinship Caregivers – Caregiver Service Needs

- DFTA and ACS Caregivers were both likely to need and not receive **Respite care** and **Information about available services**.



| Service for caregiver | GRC kinship caregivers (%) | | ACS kinship caregivers (%) | |
|---|---|---|---|---|
| | Needed and received | Needed but did not receive | Needed and received | Needed but did not receive |
| Counseling | 33 | 15 | 30 | 12 |
| Help obtaining government benefits | 63 | 12 | 44 | **26** |
| Information about available services | 30 | **29** | 38 | **23** |
| Legal services | 37 | 18 | 51 | 16 |
| Respite care | 27 | **26** | 29 | **27** |
| Support group services | 27 | 19 | 27 | 7 |

NOTE: Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (GRC=890; ACS=1,600).
SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.

# Older Adult Caregivers – Caregiver Service Needs

- **Respite care** is the most frequently needed but not received service.
- Significant levels of unmet need for **Information**, **Legal services**, and **Counseling**.

| **Service for caregiver** | **DFTA caregivers (%)** | | **AARP caregivers (%)** | |
|---|---|---|---|---|
| | **Needed and received** | **Needed but did not receive** | **Needed and received** | **Needed but did not receive** |
| Counseling | 23 | 38 | 19 | 27 |
| Help obtaining government benefits | 34 | 22 | 31 | 21 |
| Information about available services | 33 | 39 | 40 | 32 |
| Legal services | 26 | 39 | 18 | 37 |
| Respite care | 21 | 48 | 17 | 40 |
| Support group services | 25 | 33 | 15 | 23 |

NOTE: Respondents could report more than one service. Percentages for a service do not sum to 100 because the table does not report the category for respondents who did not need the service. Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).
SOURCE: Family Caregiving for Older Adults: 2017.

# Caregivers for Adults with Disabilities – Satisfaction with Caregiver Services

- Caregivers are generally satisfied with services they receive for themselves.

| | **Caregivers who received the service and reported they were Satisfied** |
|---|---|
| **Service for caregiver** | **Percent** |
| Counseling | **49** |
| Help obtaining government benefits | **69** |
| Information about available services | **74** |
| Legal services | **49** |
| Respite care | 35 |
| Support group services | 34 |

NOTE: For each service, percentages are based on the estimated number of DFTA and AARP caregivers reporting that they received the service—**counseling** (90); **help obtaining benefits** (190); **information about available services** (180); **legal services** (110); **respite care** (140), and **support group** (60).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kinship Caregivers – Satisfaction with Caregiver Services

- Kinship Caregivers are generally satisfied with services they do receive, especially **support groups** and **counseling**.

| | **Caregivers who received the service and reported Fully or Partially Satisfied** | |
|---|---|---|
| **Service for caregiver** | **GRC kinship caregivers (%)** | **ACS kinship caregivers (%)** |
| Counseling | 77 | 71 |
| Help obtaining government benefits | **59** | 74 |
| Information about available services | **59** | 72 |
| Legal services | 70 | 64 |
| Respite care | 90 | **54** |
| Support group services | 78 | 77 |

NOTE: For each service, percentages are based on the estimated number of GRC and ACS caregivers reporting that they received the service—**counseling** (GRC=290, ACS=480); **help obtaining benefits** (GRC=570, ACS=700); **information about available services** (GRC=270, ACS=610); **legal services** (GRC=330, ACS=820); **respite care** (GRC=240, ACS=460), and **support group** (GRC=240, ACS=420).

SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.

# Older Adult Caregivers –
Satisfaction with Caregiver Services

- Older Adult Caregivers are generally satisfied with services they do receive, but are least satisfied with **Respite care**.

| | **Caregivers who received the service and reported Fully or Partially Satisfied** | |
|---|---|---|
| **Service for caregiver** | **DFTA caregivers (%)** | **AARP caregivers (%)** |
| Counseling | 54 | 58 |
| Help obtaining government benefits | 59 | 52 |
| Information about available services | 52 | 57 |
| Legal services | 61 | 34 |
| Respite care | 38 | 9 |
| Support group services | 55 | 56 |

NOTE: For each service, percentages are based on the estimated number of DFTA and AARP caregivers reporting that they received the service—**counseling** (DFTA=2,200, AARP=1,500); **help obtaining benefits** (DFTA=3,200, AARP=2,400); **information about available services** (DFTA=3,100, AARP=3,100); **legal services** (DFTA=2,400, AARP=1,400); **respite care** (DFTA=2,000, AARP=1,300), and **support group** (DFTA=2,300, AARP=1;100).
SOURCE: Family Caregiving for Older Adults: 2017.

# Caregivers for Adults with Disabilities – Care Recipient Service Needs

- For the people they care for, caregivers were likely to need and not receive **Housing Support**, **Homecare**, **Networking**, and **Information about available services**.

| **Service for adult with disabilities** | **Percent** | |
|---|---|---|
| | **Needed and received** | **Needed but did not receive** |
| Day treatment center | 42 | 12 |
| Help obtaining government benefits | 39 | 17 |
| Homecare | **28** | **21** |
| Housing support | **6** | **26** |
| Information about available services | **40** | **21** |
| Medical supplies, health equipment, etc. | 32 | 15 |
| Networking activities | **18** | **22** |
| Transportation | 54 | 16 |

NOTE: Percentages for a service do not sum to 100 because the table does not report the category for respondents who did not need the service. Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (510).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kinship Caregivers – Care Recipient Service Needs

- For the minors they care for, DFTA and ACS Kinship Caregivers were likely to need and not receive **Childcare**, and more for DFTA.

| **Service for minor** | **GRC kinship caregivers on the minors receiving care (%)** | | **ACS kinship caregivers on the minors receiving care (%)** | |
|---|---|---|---|---|
| | **Needed and received** | **Needed but did not receive** | **Needed and received** | **Needed but did not receive** |
| Counseling | 30 | 16 | 41 | 11 |
| Childcare | 26 | **21** | 28 | **24** |
| Education assistance or advocacy | 35 | **23** | 47 | 17 |
| Coordinating parental visitation | 19 | 8 | 47 | 9 |
| Homemaking services | 9 | 18 | 16 | 13 |
| Housing | 8 | **26** | 14 | 14 |
| Medical services | 45 | 12 | 69 | 9 |
| Transportation | 25 | **23** | 19 | 18 |

NOTE: Percentages for a service do not sum to 100 because the table does not report the category for respondents who did not need the service. Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (GRC=890; ACS=1,600).
SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.

# Older Adult Caregivers – Care Recipient Service Needs

- For the Older Adult cared for, caregivers were most likely to need and not receive **Social Activities**, as well as **Information**, **Homecare**, and **Transportation**.

| Service | DFTA Caregivers on the People in their Care (%) | | AARP Caregivers on the People in their Care(%) | |
|---|---|---|---|---|
| | **Needed and received** | **Needed but did not receive** | **Needed and received** | **Needed but did not receive** |
| Help obtaining government benefits | 43 | 22 | 33 | 21 |
| Homecare | **47** | **29** | **39** | **29** |
| Home delivered meals or pantry services | 27 | 22 | 25 | 18 |
| Housing services | 15 | 17 | 7 | 18 |
| Information about available services | **25** | **33** | **41** | **21** |
| Medical supplies, health equipment, etc. | 50 | 24 | 46 | 20 |
| Transportation | **47** | **28** | **46** | **22** |
| Social activities | **19** | **34** | **12** | **24** |

NOTE: Percentages for a service do not sum to 100 because the table does not report the category for respondents who did not need the service. Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).

SOURCE: Family Caregiving for Older Adults: 2017.

# Caregivers for Adults with Disabilities – Satisfaction with Care Recipient Services

- Caregivers were generally satisfied with services they do receive, with the exceptions of **Homecare** and **Transportation**.

| | **Caregivers who received the service for a minor and reported they were Satisfied** |
|---|---|
| **Service for caregiver** | **Percent** |
| Day treatment center | 60 |
| Help obtaining government benefits | 69 |
| Homecare | **28** |
| Housing support | 52 |
| Information about available services | 72 |
| Medical supplies, health equipment, etc. | 77 |
| Networking activities | 68 |
| Transportation | **27** |

NOTE: Respondents could report more than one service. NOTE: For each service, percentages are based on the estimated number of DFTA and AARP caregivers reporting that the older adults in their care received the service—**day treatment center** (210); **help obtaining benefits** (200); **homecare** (140); **housing issues** (30); **information about available services** (200); **medical supplies, health equipment, or assistive devices** (160); **transportation** (90), and **social activities** (280).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kinship Caregivers – Satisfaction with Care Recipient Services

- Kinship Caregivers are generally satisfied with services they do receive for their care recipient.

| | **Caregivers who received the service for a minor and reported they were Satisfied** | |
|---|---|---|
| **Service for minor** | **GRC kinship caregivers (%)** | **ACS kinship caregivers (%)** |
| Counseling | 72 | **58** |
| Childcare | 71 | 65 |
| Education assistance or advocacy | 72 | 72 |
| Coordinating parental visitation | 55 | 62 |
| Homemaking services | 80 | 82 |
| Housing | 75 | 83 |
| Medical services | 83 | 87 |
| Transportation | **64** | **52** |

NOTE: For each service, percentages are based on the estimated number of GRC and ACS caregivers reporting that the minors in their care received the service—**counseling** (GRC=260, ACS=650); **childcare** (GRC=230, ACS=450); **education assistance or advocacy** (GRC=310, ACS=760); **coordinating parental visitation** (GRC=170, ACS=750); **homemaking services** (GRC=80, ACS=260); **housing** (GRC=80, ACS=230); **medical services** (GRC=410, ACS=1,100), and **transportation** (GRC=220, ACS=300).
SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.

# Older Adult Caregivers – Satisfaction with Care Recipient Services

- Caregivers are largely satisfied with services their care recipient receives. **Homecare** and **Housing issues** have the lowest levels of satisfaction across groups.

| | **Caregivers who received the service and reported Fully or Partially Satisfied** | |
|---|---|---|
| **Service for caregiver** | **DFTA caregivers (%)** | **AARP caregivers (%)** |
| Help obtaining government benefits | 66 | 73 |
| Homecare | **47** | **16** |
| Home delivered meals or pantry services | 76 | 73 |
| Housing services | **56** | **#** |
| Information about available services | 59 | 52 |
| Medical supplies, health equipment, etc. | 71 | 49 |
| Transportation | 62 | 18 |
| Social activities | 64 | 70 |

# Too few cases to report.

NOTE: For each service, percentages are based on the estimated number of DFTA and AARP caregivers reporting that the older adults in their care received the service—**help obtaining benefits** (DFTA=4,100, AARP=2,500); **homecare** (DFTA=4,400, AARP =3,000); **home delivered meals or pantry services** (DFTA=2,600, AARP =1,900); **housing services** (DFTA=1,400, AARP=560); **information about available services** (DFTA=2,400 AARP=3,100); **medical supplies, health equipment, or assistive devices** (DFTA=4,700, AARP=3,500); **transportation** (DFTA=4,400, AARP=3,500), and **social activities** (DFTA=1,800, AARP=920).

SOURCE: Family Caregiving for Older Adults: 2017.

# Caregivers for Adults with Disabilities – Barriers to Services

- Commonly noted barriers for **Respite care** included Financial issues, Waitlists, and Not knowing if the service is available**. Counseling,** an area with high unmet need, saw high responses on barriers as well.

| | Difficulty Experienced | | | | | |
|---|---|---|---|---|---|---|
| **Service for caregiver or care recipient** | **Don't know if service is available** | **Difficulty speaking to staff in English** | **Embarrassed to request/ receive** | **Financial issues** | **Difficult to access provider** | **Waiting lists** |
| Counseling/Therapy | 10 | 1 | 8 | 9 | 9 | 6 |
| Help obtaining government benefits | 9 | 1 | 6 | 11 | 6 | 6 |
| Respite care | **13** | 1 | 3 | **16** | 9 | **15** |
| Day treatment center | 6 | 1 | 1 | 6 | 9 | 7 |
| Transportation | 9 | # | 3 | 5 | 5 | 1 |
| Not applicable | 38 | 64 | 57 | 41 | 45 | 43 |

# Too few cases to report.
NOTE: Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table (510).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kinship Caregivers – Barriers to Services

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- GRC Caregivers– Saw the largest barriers from Lack of knowledge if service was available; 11% Financial issues. on Legal services; 20% Waitlist on Housing.

| | Don't know if service is available | | Difficulty speaking to staff in English | | Embarrassed to request/ receive | | Financial issues | | Difficult to access provider | | Waiting lists | | Other difficulty | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Service for caregiver or care recipient** | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| Counseling/Therapy | **18** | 83 | 1 | 99 | 2 | 98 | # | 98 | 6 | 94 | 4 | 96 | # | 100 |
| Help obtaining government benefits | 8 | 93 | 2 | 98 | 2 | 98 | 3 | 97 | 4 | 96 | 3 | 97 | 3 | 97 |
| Legal services | **16** | 84 | 3 | 97 | 2 | 99 | **11** | 89 | 4 | 96 | 2 | 98 | # | 99 |
| Education assistance/advocacy | **14** | 86 | 3 | 97 | # | 100 | 4 | 97 | 8 | 92 | 2 | 98 | * | 100 |
| Housing | **17** | 83 | 1 | 99 | # | 99 | 10 | 90 | 2 | 98 | **20** | 80 | # | 99 |
| Not applicable | 52 | 48 | 84 | 16 | 85 | 16 | 71 | 29 | 73 | 27 | 65 | 35 | 70 | 30 |

- ACS – 21% Lack of knowledge if available on **Housing**; 17% Financial issues on **Legal services**.

| | Don't know if service is available | | Difficulty speaking to staff in English | | Embarrassed to request/ receive | | Financial issues | | Difficult to access service | | Waiting lists | | Other difficulty | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Service | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No | Yes | No |
| Counseling/Therapy | **13** | 87 | * | 100 | 4 | 97 | # | 99 | 3 | 97 | # | 99 | 3 | 97 |
| Help obtaining government benefits | 9 | 91 | * | 100 | # | 98 | # | 99 | # | 98 | 5 | 95 | # | 99 |
| Legal services | **12** | 88 | # | 99 | * | 100 | **17** | 84 | # | 98 | 3 | 98 | 6 | 94 |
| Education assistance/advocacy | 9 | 91 | * | 100 | # | 99 | # | 98 | 4 | 96 | 4 | 96 | # | 99 |
| Housing | **21** | 79 | # | 99 | # | 99 | 3 | 97 | * | 100 | 4 | 96 | 5 | 96 |
| Not applicable | 54 | 47 | 88 | 12 | 85 | 15 | 72 | 28 | 80 | 20 | 75 | 25 | 51 | 49 |

• Less than 1 percent # Too few cases for a reliable estimate. NOTE: Percentages may not sum to 100 because of rounding.

# Older Adult Caregivers – Barriers to Services

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## **DFTA Caregivers** – Not knowing if a service was available was a barrier.

| | **Difficulty Experienced** | | | | | |
|---|---|---|---|---|---|---|
| **Service for caregiver or care recipient** | **Don't know if service is available** | **Difficulty speaking to staff in English** | **Embarrassed to request/ receive** | **Financial issues** | **Difficult to access provider** | **Waiting lists** |
| Counseling/Therapy | 29 | 3 | 16 | 10 | 7 | 3 |
| Help obtaining government benefits | 15 | 4 | 6 | 15 | 11 | 9 |
| Legal services | 31 | 3 | 3 | 25 | 6 | 4 |
| Respite care | 38 | 3 | 5 | 20 | 7 | 4 |
| Support group | 26 | 1 | 12 | 4 | 9 | 2 |
| Not applicable | 30 | 66 | 56 | 42 | 50 | 55 |

## **AARP Caregivers** – Not knowing if a service was available was a barrier.

| | **Difficulty Experienced** | | | | | |
|---|---|---|---|---|---|---|
| **Service for caregiver or care recipient** | **Don't know if service is available** | **Difficulty speaking to staff in English** | **Embarrassed to request/ receive** | **Financial issues** | **Difficult to access provider** | **Waiting lists** |
| Counseling/Therapy | 16 | # | 12 | 9 | 5 | 2 |
| Help obtaining government benefits | 16 | # | 7 | 16 | 9 | 10 |
| Legal services | 25 | 1 | 4 | 23 | 9 | 5 |
| Education assistance/advocacy | 25 | 1 | 5 | 20 | 6 | 5 |
| Housing | 25 | # | 8 | 6 | 6 | 3 |
| Not applicable | 25 | 74 | 62 | 44 | 58 | 59 |

# Too few cases to report.
NOTE: Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).
SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Caregivers for Adults with Disabilities – Employment & Income Security

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- The majority of caregivers are employed full- or part-time.
- Most caregivers report care affecting their job.
- 49% report barely managing to get by or say they cannot make ends meet.

| **Indicator of living situation** | **Percent** |
|---|---|
| **Employment status[1]** | |
| Employed full time | 40 |
| Employed part time | 23 |
| Not employed or looking for work | 12 |
| Retired | 25 |
| **Effect of caregiving on job** | |
| Affected job | 75 |
| Did not affect job | 25 |
| **Financial situation[1]** | |
| Cannot make ends meet | 11 |
| Barely manage to get by | 38 |
| Have enough to manage | 45 |
| Have more than enough to manage | 7 |

[1] Percentages are based on caregivers who were employed during the three years preceding the survey (380).

NOTE: Percentages may not sum to 100 because of rounding or multiple responses. Percentages are based on estimated numbers of caregivers responding to the questions reported in this table (510).

SOURCE: Family Caregiving for Adults with Disabilities: 2017.

# Kindship Caregivers – Employment & Income Security

- GRC caregivers are more likely to be Retired (73%) and the majority (62%) report Barely managing to get by, with an additional 9% that Cannot make ends meet.
- ACS caregivers are more likely to report being Employed full- or part-time (38% and 18%). 60% of caregivers report having caregiving affect employment. 31% report Barely managing to get by and 2% Cannot make ends meet.

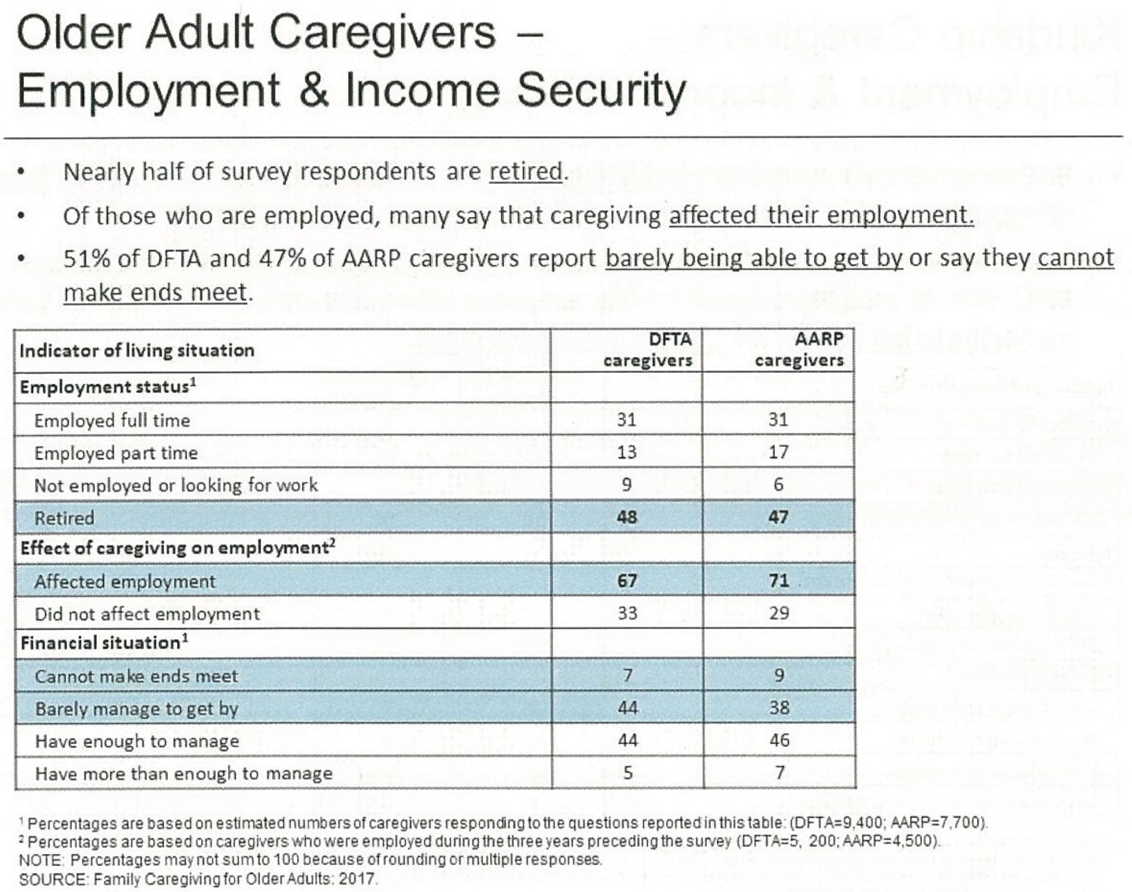
| **Indicator of living situation** | **GRC kinship caregivers** | **ACS kinship caregivers** |
|---|---|---|
| **Employment status[1]** | | |
| Employed full time | 9 | **38** |
| Employed part time | 8 | **18** |
| Not employed or looking for work | 10 | 14 |
| Retired | **73** | 29 |
| **Effect of caregiving on employment[2]** | | |
| Affected employment | **71** | **60** |
| Did not affect employment | 29 | 40 |
| **Financial situation[1]** | | |
| Cannot make ends meet | **9** | **2** |
| Barely manage to get by | **62** | **31** |
| Have enough to manage | 28 | 63 |
| Have more than enough to manage | # | 4 |

*Too few cases to report data. NOTE: Percentages may not add to 100 because of rounding.

[1] Percentages are based on caregivers who were employed during the three years preceding the survey (GRC=270; ACS=1,100).

[2] Percentages are based on estimated numbers of caregivers responding to the questions reported in this table: (GRC=890; ACS=1,600).

SOURCE: Surveys on Family Caregiving for Minors Under 18: 2017.



## Older Adult Caregivers – Employment & Income Security

- Nearly half of survey respondents are retired.
- Of those who are employed, many say that caregiving affected their employment.
- 51% of DFTA and 47% of AARP caregivers report barely being able to get by or say they cannot make ends meet.

| Indicator of living situation | DFTA caregivers | AARP caregivers |
|---|---|---|
| **Employment status**[1] | | |
| Employed full time | 31 | 31 |
| Employed part time | 13 | 17 |
| Not employed or looking for work | 9 | 6 |
| Retired | **48** | **47** |
| **Effect of caregiving on employment**[2] | | |
| Affected employment | **67** | **71** |
| Did not affect employment | 33 | 29 |
| **Financial situation**[1] | | |
| Cannot make ends meet | 7 | 9 |
| Barely manage to get by | 44 | 38 |
| Have enough to manage | 44 | 46 |
| Have more than enough to manage | 5 | 7 |

[1] Percentages are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).
[2] Percentages are based on caregivers who were employed during the three years preceding the survey (DFTA=5, 200; AARP=4,500).
NOTE: Percentages may not sum to 100 because of rounding or multiple responses.
SOURCE: Family Caregiving for Older Adults: 2017.

Since releasing the report, Operations has convened a working group co-chaired by DFTA. The working group includes experts from ACS, MOPD, the Department of Education, AARP, Health + Hospitals, the Commission on Gender Equity, the Office of Management and Budget, and the City Council, among others. The full working group is divided into four subcommittees – Communications, Policy, Services, and Economic Stability – with the goal of creating recommendations that address the areas of greatest need identified by the survey. The process is well underway.

Thank you, Chairwoman Chin, for taking the time to speak with us today. I look forward to answering your questions.

FOR THE RECORD

## New York City Council Hearing
## Oversight - Supporting Unpaid Caregivers.

Testimony of Ian Magerkurth, Director of Government Affairs for New York State Alzheimer's Association

Good morning:

My name is Ian Magerkurth, the Director of Government Affairs for New York State for the Alzheimer's Association.

I appreciate the opportunity to testify today on this oversight hearing on supporting unpaid caregivers and I would like to begin by applauding Mayor de Blasio, Chairwoman Chin together with Speaker Mark-Viverito and the New York City Council for their commitment and support for the city's aging community and for working to enact Local Law 97 of 2016, which led to the recent findings in DFTA's 2017 "Survey of Informal Caregivers in New York City".

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's advocacy, research and support. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

We provide education, care and support to New Yorkers affected by Alzheimer's and other dementias through our free in-person and online programs for caregivers, professionals, and the public on a wide range of topics such as diagnosis, early warning signs, and the need for caregiver support and respite. We have a diverse and multilingual staff of specialists and master's-level clinicians that can work with New Yorkers in need, in person or over the phone and through our free 24/7 Helpline.

We advocate for the needs and rights of those facing Alzheimer's disease, helping to educate policymakers on the Alzheimer's crisis and engage them in our efforts to fight the disease.

I want to focus on the findings of the report in regard to adults caring for family member(s) aged 60 or over, including adults with Alzheimer's disease or other dementia. There is no one-size-fits all formula when it comes to Alzheimer's care. Needs change at different stages of the disease and each family's situation is unique. Deciding on who is best suited for providing long term caregiving tasks can be a tough decision.

Approximately 390,000 people in New York State have Alzheimer's and more than 1 million New Yorkers provide unpaid care for people with Alzheimer's and other dementias. Caring for these loved ones can take a severe emotional, physical and financial toll on the individuals providing it. At the Alzheimer's Association, we face this public health challenge head on by providing interventions that address the continuum of care.

- More than 1 million New Yorkers provide unpaid care for people with Alzheimer's and other dementias

- Fifty-nine percent rated their emotional stress as high or very high. Additionally, about 40 percent of family caregivers suffer from depression.

- Caregivers experience work-related challenges when they begin caregiving. Fifty-four percent had to go in late or leave early, and 15 percent had to take a leave of absence.

- On average, care contributors lose more than $15,000 in annual income as a result of reducing or quitting work to meet the demands of caregiving.

By 2030, the segment of the population age 65 and older will increase substantially and older Americans will make up approximately 20% of the total population. As the number of older Americans grows rapidly so too will the number of people with Alzheimer's. The progression of Alzheimer's disease is slow and debilitating and as such contributes to the public health impact of Alzheimer's disease because much of that time with the disease is spent in disability. As such, the growing elder population as well as the growing population of New Yorkers will rely on the critical services provided by the Department for the Aging and its City funded subcontractors.

We applaud, Department for the Aging for its thorough and comprehensive survey and including stakeholders in the development, data collection and interpretation of the survey's findings.

- Availability of services: The survey found that many caregivers over age 60 ( between 73% and 74%) did not know about services available to help them.
- Respite: for all caregiver groups, respite care was among the top four services in demand but it was also among the services with high levels of unmet need. Caregiving is demanding — and it's normal to need a break. Respite services benefit the person with dementia as well as the caregiver, providing a temporary rest from caregiving, while the person with Alzheimer's continues to receive care in a safe environment. Using respite services can support and strengthen one's ability to be a caregiver as well as provide Time to relax, socialize, take care of errands such as shopping, exercising, getting a haircut or going to the doctor.
- Ethnic Communities- a key limitation of the caregiver study was that the sample of caregivers of older adults were mostly white and Black and were primarily (90% and 92%) English speakers. New York has by far the largest immigrant senior population of any U.S. city. According to the Center for Urban Future, as of 2015, 49.5 % of New Yorkers ages 65 or older are foreign-born and by 2020 immigrant seniors will be the majority. Today, there are now 23 out of the 55 Census-defined neighborhoods citywide where the majority of seniors are immigrants. Many seniors and their caregivers have limited English proficiency which impacts their ability to seek and receive services. As such, the Department for the Aging report does not give an accurate picture of the challenges faced by the ethnically and linguistically diverse group of caregivers in New York City.

The Alzheimer's Association is encouraged by our review of DFTA's report and while New York City has made significant investments to support caregiver services, and is poised to be a leader in addressing the burdens caregivers face. As reflected in the report, the City must do more to support its large population of unpaid caregivers, especially with information about available services, providing respite care and reaching out to linguistic and ethnic groups that may not be aware of services as well as providing culturally competent services. We look forward to continuing to work with the New York City Council, DFTA, and other government and community partners in supporting these invaluable members of our community.

Thank you for your time and consideration.

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

CAREGIVER PROGRAM OF SNAP
133-33 Brookville Boulevard, Suite LL5
Rosedale, NY 11422
T: (718) 527-5380 F: (718) 525-8894
E: Caregiversfirst@aol.com * W: www.snapqueens.org

# TESTIMONY

# CITY COUNCIL COMMITTEE ON AGING

# HEARING

WEDNESDAY, NOVEMBER 29, 2017

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MARCIA FRIEDLANDER ,LCSW

CLINICAL DIRECTOR, CAREGIVER PROGRAM

GOOD MORNING TO ALL DISTINGUISHED MEMBERS OF THE COMMITTEE ON AGING, COMMISSIONER CORRADO, DISTINGUISHED STAFF OF THE NEW YORK CITY DEPARTMENT FOR THE AGING AND COMMUNITY COLLEAGUES. THANK YOU FOR CONDUCTING THIS HEARING TODAY. MY NAME IS MARCIA FRIEDLANDER. I AM THE CLINICAL DIRECTOR OF SERVICES NOW FOR ADULT PERSONS, INC'S (SNAP) CAREGIVER PROGRAM. SNAP IS DEDICATED TO ADDRESSING THE NEEDS OF THE ETHNICALLY AND ECONOMICALLY DIVERSE SENIOR POPULATION IN QUEENS. THE AGENCY IS HOME TO BOTH INNOVATIVE AND NEIGHBORHOOD SENIOR CENTERS AS WELL AS A VIRTUAL SENIOR CENTER FOR THOSE SENIORS WHO WOULD LIKE TO PARTICIPATE IN CENTER PROGRAMS AND ACTIVITIES BUT ARE PHYSICALLY UNABLE TO ATTEND THE SENIOR CENTERS. TRANSPORTATION, CASE MANAGEMENT, HOME DELIVERED MEALS, FRIENDLY VISITOR, AS WELL AS SNAP'S NEWLY ESTABLISHED SOCIAL ADULT DAY PROGRAM ARE ALL PART OF THE CONTINUUM OF SERVICES WHICH SNAP PROVIDES TO THE SENIOR COMMUNITY. THE CAREGIVER PROGRAM OF SNAP HAS BEEN PROVIDING BOTH EMOTIONAL, FINANCIAL AND RESPITE SUPPORT TO INFORMAL CAREGIVERS SINCE JANUARY 2003. IN THESE PAST 14 YEARS SNAP HAS GAINED A SIGNIFICANT AMOUNT OF EXPERIENCE AND KNOWLEDGE WORKING WITH CAREGIVERS IN QUEENS. WE WOULD LIKE TO SHARE OUR THOUGHTS WITH YOU THIS MORNING.

INDIVIDUALS AGES 85YEARS OF AGE AND OLDER CONTINUE TO BE AMONGST THE FASTEST GROWING OF THE ELDERLY POPULATION. THIS COHORT OF ADVANCED AGE INDIVIDUALS CREATES AN INCREASING DEMAND FOR LOVED ONES TO BECOME ACTIVELY ENGAGED IN THEIR CARE. AS A RESULT, SUPPORT FOR CAREGIVERS IN THIS ROLE HAS BECOME VITAL IN REGARD TO HELPING OLDER INDIVIDUALS AGE IN PLACE AND AVOID UNWANTED AND COSTLY INSTITUTIONALIZATION.

FROM EXPERIENCE SNAP HAS RECOGNIZED THAT MOST CAREGIVERS CONTACT OUR OFFICE WHEN THEY ARE ALREADY FEELING OVERWHELMED. INDIVIDUAL RESPITE TENDS TO BE THE MOST FREQUENTLY REQUESTED SERVICE WITH CAREGIVERS WANTING A HOME HEALTH AIDE TO COME TO THE CARE RECEIVERS HOME. AS CAREGIVERS BECOME FAMILIAR AND COMFORTABLE WITH BOTH THE PROGRAM AND THE STAFF, THEY ALSO BECOME OPEN TO PARTICIPATING IN OTHER SERVICES SUCH AS COUNSELING, SUPPORT GROUPS AND EDUCATIONAL WORKSHOPS. SIMILAR TO THE WAY MEALS ON WHEELS OFTEN OPENS THE DOOR TO OTHER CASE MANAGEMENT ASSISTANCE, SNAP FINDS THAT RESPITE IS THE CONCRETE SERVICE THAT OPENS THE DOOR TO EMOTIONAL SUPPORT FOR CAREGIVERS. AT FIRST CAREGIVERS MAY BELIEVE THAT RESPITE SERVICES IS ALL THEY NEED TO MANAGE. THEY OFTEN COME TO REALIZE THAT BY TAKING

ADVANTAGE OF BOTH RESPITE AND EMOTIONAL SERVICES THEY ARE BETTER ABLE TO BALANCE THE MYRIAD OF RESPONSIBILITIES THEY FACE IN THEIR CAREGIVING ROLE.

THE MAJORITY OF SNAP'S CAREGIVER CLIENTS ARE WOMEN WHO ARE IN THE POSITION OF JUGGLING BOTH WORK AND CAREGIVING. ADULT CHILDREN CAREGIVERS ARE OFTEN FORCED TO COMPROMISE THEIR WORK LIFE IN ORDER TO MEET THE NEEDS OF THEIR ELDERLY PARENTS, AND/OR RELATIVES. WOMEN AND MINORITY CAREGIVERS ARE MOST LIKELY TO REDUCE WORK HOURS OR LEAVE WORK COMPLETELY TO CARE FOR AN OLDER ADULT. CREATING WAYS OF SUPPORTING THESE ADULT CHILDREN CAREGIVERS SO THAT THEY MAY REMAIN IN THE WORKFORCE AND EFFECTIVELY BALANCE BOTH WORK AND CAREGIVING RESPONSIBILITIES IS AN ESSENTIAL PART OF CAREGIVER SUPPORT. THE NEW PAID NEW YORK STATE FAMILY LEAVE ACT WILL GO INTO EFFECT IN JANUARY 2018 AND WILL HELP TO PROMOTE THIS BALANCE FOR WORKING CAREGIVERS IN THE FUTURE. HOWEVER, WE MUST CONSIDER ADDITIONAL WAYS OF PROVIDING ECONOMIC STABILITY AND POLICIES THAT SUPPORT CAREGIVERS IN THE WORKFORCE. THIS WILL BENEFIT BOTH EMPLOYERS AND EMPLOYEES. EMPLOYEES WILL BE ABLE TO CONTINUE WORKING AND NOT HAVE TO LEAVE THE WORKFORCE EARLIER THAN THEY WOULD HAVE PLANNED, AND EMPLOYERS

WILL BE ABLE TO KEEP EXPERIENCED WORKERS ON STAFF. HELPING CAREGIVERS CONTINUE TO CONTRIBUTE FINANCIALLY TOWARD THEIR FUTURE WITHOUT HAVING TO LEAVE THE WORKFORCE SOONER BENEFITS THE CAREGIVER INTO RETIREMENT.

SNAP HAS ALSO RECOGNIZED THAT MOST CAREGIVERS NEED AFFORDABLE LEGAL SERVICES WITH ACCESS TO LEGAL INFORMATION AND GUIDANCE. THESE CAREGIVERS ARE ALREADY PAYING OUT OF POCKET CAREGIVER EXPENSES. MANY HAVE DIFFICULTY COVERING THEIR OWN COSTS WHILE ALSO DEALING WITH EXPENSES FROM THEIR LOVED ONES. PRIVATE ELDER LAW ATTORNEYS ARE UNAFFORDABLE FOR MANY PEOPLE, AND LAW SCHOOLS OR AFFORDABLE LEGAL SERVICES OFTEN HAVE WAIT LISTS AND/OR ARE LIMITED IN WHAT THEY DO.

ANOTHER AREA OF CONCERN IN REGARD TO CAREGIVING IS RELATED TO REACHING DIVERSE COMMUNITIES WITH CAREGIVER SUPPORT. CULTURAL DIFFERENCES OFTEN ACT AS BARRIERS TO ACCEPTING HELP. EDUCATION FOR STAFF, CAREGIVERS AND CARE RECEIVERS IS VITAL IF WE ARE TO REACH DIVERSE POPULATIONS. TO START WITH, STAFF MUST GROW IN AWARENESS AND SENSITIVITY TOWARD CULTURAL NUANCES. CAREGIVERS FROM DIVERSE CULTURES MAY FEEL RELUCTANT TO ACCEPT ASSISTANCE AS THEY FEAR THEIR

OLDER LOVED ONE'S REACTION TO SEEKING HELP FROM THE OUTSIDE. GOING OUTSIDE OF THE FAMILY IS OFTEN FROWNED UPON AND FEARED WITHIN THESE COMMUNITIES. EDUCATION IN THIS REGARD WILL TAKE TIME AND EFFORT ON THE PART OF PROFESSIONALS IF WE ARE TO MAKE A DIFFERENCE IN THESE COMMUNITIES.

HELPING CAREGIVERS IDENTIFY AS SUCH CONTINUES TO PLAY A ROLE IN THEIR SEEKING SERVICES. IDENTIFYING WHERE TO FIND SUPPORT CONTINUES TO BE A CHALLENGE FOR CLIENTS AND PROGRAMS ALIKE. STAFF IS LIMITED IN TERMS OF RESOURCES, BUDGETS AND TIME FOR THE KIND OF OUTREACH NECESSARY TO MAKE CAREGIVING A HOUSEHOLD PHRASE. A PUBLIC AWARENESS CAMPAIGN WOULD HELP MAKE CAREGIVING A FAMILIAR TERM AND WOULD BEGIN TO MAKE REACHING OUT FOR ASSISTANCE AN ACCEPTABLE PRACTICE.

FINALLY, IN TERMS OF THE PROFESSIONALS WHO WORK IN SNAP'S CAREGIVER PROGRAM IT SHOULD BE MENTIONED THAT SNAP'S STAFF HAS EITHER BEEN WITH THE PROGRAM SINCE ITS INCEPTION OR HAS BEEN WITH IT FOR MULTIPLE YEARS. THESE PROFESSIONALS BRING A WEALTH OF EXPERIENCE AND DEDICATION TO THE TEAM AND ARE AN INTEGRAL PART OF CREATING A QUALITY PROGRAM. THEY ARE ABLE TO RECOGNIZE THE VALUE OF THE WORK THAT

INFORMAL CAREGIVERS PROVIDE AND ARE ABLE TO HELP THESE PEOPLE ON MULTIPLE LEVELS. SALARIES FOR THESE COMMITTED WORKERS SHOULD REFLECT THE PROFESSIONALISM THAT IS NEEDED TO CARRY OUT THE PROGRAM SERVICES. THESE WORKERS HAVE PROVIDED SERVICES TO CAREGIVERS FOR YEARS WITHOUT THE BENEFIT OF SALARY INCREASES AS BUDGETS DO NOT ALLOW FOR IT. WHENEVER ADDITIONAL FUNDING IS GIVEN SALARY NEEDS FOR EXISITING STAFF ARE NEVER PART OF THE EQUATION. IN ADDITION SNAP'S CAREGIVER PROGRAM IS FULLY STAFFED BY WOMEN, MANY OF WHOM HAVE BEEN CAREGIVERS OR WILL BE CAREGIVERS IN THE FUTURE. WHAT MESSAGE DO WE SEND THE STAFF WHEN WE DISCUSS THE IMPORTANCE OF HELPING WOMEN CAREGIVERS REMAIN FINANCIALLY VIABLE WHILE, AT THE SAME TIME AVOID ANY DISCUSSION OF REMUNERATION FOR PROFESSIONALS PROVIDING SERVICES TO THESE CAREGIVERS? CARING FOR CLIENTS, FAMILIES AND STAFF ARE ALL PART OF A BALANCED SYSTEM THAT WORKS WELL FOR ALL.

SNAP RECOGNIZES AND APPRECIATES THE FOCUS THAT GOVERNMENT HAS PLACED ON ALLEVIATING THE STRESS OF NEW YORK CITY CAREGIVERS. WE LOOK FORWARD TO CONTINUING IN OUR WORK TOGETHER AND THANK YOU FOR THEOPPORTUNITY TO SHARE TODAY.

AARP Real Possibilities in

New York City

# Testimony of
# Chris Widelo, Associate State Director
# AARP New York

# New York City Council
# Committee on Aging

# Oversight - Supporting Unpaid Caregivers

# November 29, 2017

# City Hall
# New York, New York

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

Good morning Chairwoman Chin and members of the Aging Committee. My name is Chris Widelo and I am AARP's Associate State Director for New York City. On behalf of our 850,000 members age 50 and older in New York City, I want to thank you for the opportunity to testify today on the topic of unpaid family caregivers.

Family caregivers provide an invaluable resource in caring for their loved ones at home – many are 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 and more $13 billion here in New York City. Thanks to family caregivers' commitment, hundreds of thousands 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.

I want to applaud the City's Department for the Aging on their recent survey of informal caregivers in NYC. It's a great first step in addressing the needs of New York City's unpaid caregivers. There are more than a few highlights that stand out from AARP's perspective:

- There are an estimated 900,000 to 1.3 million unpaid caregivers in New York City

- A majority of caregivers are women and at least 50 years old
- More than half of caregivers provide at least 30 hours of care each week
- At least one-third of each caregiver group struggles financially
- Information about available services is in the top three most needed services for all caregiver types
- One of the services with the highest levels of unmet need was respite care—at least 1 in 4 caregivers from each group need but do not receive it
- Two of the most prevalent barriers to obtaining services are lack of knowledge regarding available services and income/financial limitations

Because so much has been said or will be said regarding services, I want to focus in more on the financial strain unpaid family caregivers experience.

A 2016 AARP report on family caregiving and out-of pocket costs concluded that family caregivers not only spend time and energy caring for an adult with care needs but also spend a significant amount of money of their own. Family caregivers are spending roughly $7,000 ($6,954) in 2016 on caregiving expenses which amounts to, on average, 20% of their total income.

The overwhelming majority of caregivers —almost 4 out of 5— (78%) are incurring out-of-pocket costs as a result of caregiving. Higher than average out-of-pocket costs are seen for several groups of caregivers including Hispanic/Latino caregivers, those caring for someone with dementia (also those engaged in many ADLs) and those caring for a loved one from a distance.

In addition to out-of-pocket costs, many caregivers are experiencing work strain and personal strain. More than half of caregivers in this study reported at least one work-related strain (e.g., a change in work hours, taking paid or unpaid time off, etc.). Many family caregivers are also dipping into their savings and cutting back on their own personal spending to accommodate for caregiving costs. For example, roughly half are cutting back on leisure spending and one in six has cut back on retirement savings. This finding raises the importance for not only education and assistance for family caregivers but also financial assistance such as a family caregiver tax credit that would help address the financial challenges of caregiving.

I want to remind everyone of an important statistic. The older adult population in New York City is expected to grow 40% between 2010 and 2040. That's the largest growth of any demographic group! Every day 10,000 people across the US turn 65 years of age. This trend will continue for the next 12 years. We are only at the beginning of a caregiving crisis.

Caregiving and how we support unpaid family caregivers is a priority for AARP nation-wide and here in New York City. We want to continue working with the City Council and the Mayor to find solutions that will best support the lives of our City's family caregivers

# REPORT SPOTLIGHTS FINANCIAL TOLL OF FAMILY CAREGIVING

Credit for Caring Act Could Help

**$6,954**

Average Out of Pocket Expenses for Family Caregivers in 2016

**$11,923**

Average Out of Pocket Expenses for Long-Distance Caregivers in 2016

## Family Caregivers Provide $470 Billion in Unpaid Care

Source: Valuing the Invaluable 2015 Update: Undeniable Progress, but Bigs Gap Remain, AARP Public Policy Institute

More than three in four family caregivers (78%) are incurring out-of-pocket costs as a result of caregiving

**78%**

**20%**

Family caregivers are spending, on average, nearly 20% of their income on caregiving activities

AARP® Real Possibilities

Source: Family Caregiving and Out-of-Pocket Costs: 2016 Report
aarp.org/caregivercosts

To learn more about the Credit for Caring Act *(H.R. 4708/ S. 2759)* visit **aarp.org/supportcaregivers**

With the solvency of the entire system at risk, and a growing population of seniors, it is critical that the administration and City Council continue to invest in, and baseline, these proven effective aging programs and supports specific to caregivers themselves. LiveOn NY supports a fair and equitable budget that supports seniors of all backgrounds in a culturally competent, respectful, and accessible manner.

We look forward to working with our elected officials to ensure that senior and caregiving issues remain a priority and are invested in as such in the coming fiscal year. Thank you again to the New York City Council and the Committee on Aging for the opportunity to testify on the needs of unpaid caregivers.

LiveOn NY
Making New York a better place to age

# New York City Council
## Committee on Aging, Council Member Margaret Chin, Chair
## Oversight Hearing on Supporting Unpaid Caregivers
## November 29, 2017

LiveOn NY thanks Chair of the Committee on Aging, Council Member Margaret Chin, and the entire Committee for holding this hearing on supporting unpaid caregivers in New York City.

LiveOn NY also thanks Mayor Bill de Blasio, Speaker Melissa Mark-Viverito, Finance Chair Julissa Ferreras-Copeland, Aging Chair Margaret Chin, and Department for the Aging Commissioner Donna Corrado for the critical investment of $4 million to the newly created Caregiving program in FY18. We are appreciative of all of the work done to make FY18 "the Year of the Senior" with an investment of $22 million to the Department for the Aging and we look forward to continuing these much needed gains in the year to come.

The Department for the Aging recently released "A Survey of Informal Caregivers in New York City" as required by Local Law 97 passed in 2016. The study highlights the difficulties that the estimated 1.3 million unpaid caregivers in New York City experience on a daily basis[1]. From lost earnings to a lack of information about available services, unpaid caregivers, a majority of whom are women, continue to need increased support and resources. More than half of caregivers studied provide at least 30 hours of care each week, and 3 out of 4 caregivers of older adults were over 55 themselves.

It is important to note that these caregivers not only support their loved ones, but New York State benefits an estimated $32 billion annually from these unpaid services[2]. Further, 28% of grandparents in New York City are responsible for raising grandchildren, which significantly alleviates strains on the foster care system and helps to develop the city's youth.[3] While caregivers are economically supporting the city and state, they are often struggling themselves financially, physically, and emotionally. More can be done to support these invaluable caregivers who reside in every district and make up every race, gender, and socioeconomic status.

Beyond unpaid caregivers, who make up the unseen workforce supporting New York City's most vulnerable, is a network of services that also provides care, support, and prevention services to seniors. The entire network of services funded by the Department for the Aging are caregiving mechanisms themselves that act as resources and options for unpaid caregivers and their loved ones. For example, social adult day programs offer peace of mind that a senior is looked after in a safe environment so a loved one can remain a part of the workforce; home-delivered meals support homebound seniors who may have nowhere else to turn for a nutritious meal; case management and home care can help a senior avoid the costly move to a nursing home by providing needed assistance with bathing and household chores. The list goes on as senior centers, NORCs, transportation services, and the entirety of the programs funded by the Department for the Aging serve a critical and cost-effective role of supporting New York's older adults.

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[1] Department for the Aging, "A Survey of Informal Caregivers in New York City", 2017.

[2] AARP, 2011

[3] Census Bureau, American Community Survey, 2013

caringkind The Heart of Alzheimer's Caregiving

360 Lexington Avenue, 4th Fl.
New York, NY 10017
caringkindnyc.org
F: 212-490-6037

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

# New York City Council

## Committee on Aging Hearing

## Support for Informal Caregivers in NYC

Council Member Margaret Chin, Chair

Wednesday, November 29, 2017

CaringKind is on the front lines every day providing a wide variety of educational and support programs, including 85 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, LGBT, and Orthodox Jewish communities and other underserved and immigrant populations.

Today's hearing is focused on providing support to New York City's unpaid or family and friend caregivers.

New York City's population is aging rapidly. As of 2010 there are an estimated 1.1 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.

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. The recent survey of informal caregivers by the Department for the Aging makes a compelling case for caregiving services across the disease and disability spectrum. ***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 dementia 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.

To increase and improve access to New York City's senior and caregiver services CaringKind 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.
- We are so pleased with the news that the City is funding Caregiver Respite Services at $4 Million, consistent with the recommendation from the Council and supported by LiveOnNY and other advocates in aging. Providing supportive services and access to respite for the caregiver is key to maintaining his or her own wellbeing and that of the

person with dementia. This includes day care, home care or a temporary placement, to allow the caregiver to attend to daily chores, get their hair cut, attend a support group, 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.

CaringKind deeply appreciates the commitment of the Committee of Aging and Chair Margaret Chin to improving the lives of New York's family caregivers. CaringKind stands ready to provide expert guidance and assistance in considering these matters and in implementing the respite and other caregiver programs.

sage | Advocacy & Services for LGBT Elders

**We refuse to be invisible**

## Testimony to the Committee on Aging of the New York City Council

**Delivered in person on November 29, 2017**
**by Jane Fialko, Care Manager for SAGE**

Councilmembers, on behalf of SAGE, thank you for holding this Committee hearing on unpaid caregivers. My name is Jane Fialko, and I am a Care Manager at SAGE.

Founded right here in NYC in 1978, SAGE has provided comprehensive social services and programs to LGBT older people and their caregivers for nearly four decades, including through our five LGBT-welcoming senior centers across the city and our comprehensive caregiving program, both of which have been funded through the Council and New York City Department for the Aging.

As many of you know, LGBT elders face myriad challenges associated with aging: declining health, diminished income, the loss of friends and family, and ageism. LGBT older adults also face invisibility, ignorance, and fear of harassment and poor treatment.

Yet, LGBT elders are far more likely to live with these challenges in isolation. LGBT older people are twice as likely to live alone; half as likely to be partnered; half as likely to have close relatives to call for help; and more than four times more likely to have no children to help them. As a result of these thin support networks, many LGBT older people have nobody to rely on. In fact, nearly 25% of LGBT older adults have no one to call in case of an emergency. Among LGBT older respondents to one survey, nearly one-third of both gay men and transgender people reported they don't know who would be their caregiver if the need arose. If an LGBT older adult has no legal family to rely on, who cares for them?

Though the statistics are troubling, the older LGBT population is a vibrant and resilient community, who have persevered by coming together and caring for their own. An example of this resilience can be found in the ways in which the LGBT community came together during the HIV/AIDS crisis. It was LGBT people who stepped up to provide caregiving support for lovers, friends and even strangers who were living with HIV/AIDS. As a result, social networks were expanded and strengthened, and survivors of that time have continued to rely on these care networks.

According to Caregiving in the U.S., a 2015 study by AARP and The National Alliance for Caregiving, there are 34.2 million Americans who provide unpaid care to another adult who is over the age of 50. The care they provide is a critical part of the aging service provider network, as it accounts for over 85% of all elder care in the U.S. These unpaid hours of care for older adults are valued at $522 billion annually.

LGBT caregivers make up 9% of the 34.2 million Americans caring for adults over age 50, which is an estimated 3 million people. Among Hispanic caregivers, 15% identify as LGBT. LGBT people become caregivers at a higher rate than their non-LGBT peers: 1 in 5 LGBT people is providing care for another adult, compared to 1 in 6 non-LGBT people. Part of the reason for this is that LGBT people have often been historically viewed by their siblings with families, as 'single' even if they are partnered, and therefore, available to take care of aging parents.

In the absence of people to rely on from their families of origin, for many LGBT people, families of choice are the cornerstones of caregiving. These chosen families provide social, emotional and physical support, and often serve as advocates when medical needs arise. However, most families of choice are not afforded any legal recognition or protection, and service providers may not think to inquire about or include these people in their work. It is important to recognize these relationships, and to provide support in completing paperwork that ensures the wishes of the care recipient are recognized.

As an LGBT person ages they may turn to their family of choice to provide care. It is common for the majority of an LGBT older adult's close friends and chosen family to be older adults themselves, which means that many older LGBT individuals rely on one another for caregiving, and a large number of LGBT older adults find themselves becoming caregivers. As peers and friends age, those caregivers may not be able to give adequate care.

The act of providing physical, emotional, and perhaps financial support to an ill or aging person can lead to isolation, stress, and eventually caregiver burnout. All caregivers are susceptible to caregiver burnout; the LGBT caregiver is likely to experience some additional factors that can increase caregiver burden and lead them to burn out more quickly. Whether an LGBT caregiver is providing care for a member of their family of origin or family of choice, it is apparent that this population is in need of meaningful and approachable direct services and support for LGBT caregivers.

To better serve LGBT elders and their caregivers, SAGE launched our Caregiving Program to provide a safe, welcoming community to help caregivers navigate their current and future needs. As they provide care for a loved one, SAGE's Caregiving Program cares for them, and in turn helps them prepare for the time in their life when they may need care. SAGE's Caregiving Program offers case management, counseling, weekly caregiver support groups, educational seminars and online resources, self-care workshops, information on benefits, respite care and supplementary support, and help for caregivers planning for their own futures.

SAGE's program is the City's only dedicated LGBT caregiving program. Supporting LGBT caregivers through programs and services is one of the best ways for the Council to have a positive impact on the lives of both LGBT caregivers and LGBT elders receiving care. Caregiver support will save money on costly long-term care and helps keep care recipients in their homes.

Thank you to the City Council for your continued commitment to our city's LGBT older people and caregivers. Your support has been instrumental in ensuring that SAGE is there for them.

As we look to a growing population of LGBT older people and an increase in unpaid caregiving, SAGE looks forward to working with the members of the Council to support LGBT caregiver and ensure that more of our city's LGBT elders can age in place.

India Home
A Center for Senior Care

Commitment to Improve
the Quality of Life

Wednesday November 29, 2017

**To: New York City Council Committee on Aging**
**From: India Home, Inc.**
**Re: Supporting Unpaid Caregivers**

Thank you for giving me this opportunity to testify in front of the Committee on Aging. My name is Lakshman Kalasapudi and I am the Deputy Director of India Home. India Home is a non-profit organization founded by community members to serve South Asian older adults. The mission of India Home is to improve the quality of life for older adults by providing through culturally appropriate social services. We provide senior center programs, case management, advocacy and awareness campaigns for South Asian seniors.

I am here today to discuss the urgent and pressing needs of unpaid caregivers in our communities. Each day, thousands and thousands of South Asians in New York City provide unpaid caregiving usually to their family members. Typically in South Asian culture, older adults live with their adult children and grandchildren in a joint family system. As such, much of the burden of caring for older adults – especially those with chronic conditions and other psychosocial needs – falls on working age adults. In addition, there is a large and growing number of older adults who themselves are caregivers to their parents, spouses, siblings, or other family members.

Both working age adults and older adults face unique challenges as unpaid caregivers. Financial stress, mental and emotional wellness, and physical health complications are common problems we have witness with our clients and their caregivers. These add undue burden to the city in other ways: unnecessary paid leave days used, loss of economic activity, and even visits to the hospital. As a result, the stressors on unpaid family caregivers must be alleviated for a healthier city.

We request the city council to increase support for caregiver programs to small organizations to reach hard to reach or isolated ethnic, religious, or linguistic communities. We are grateful that the administration has baselined $4,000,000 in FY

2018 to caregiver support programs, however, these funds generally go to large social service agencies which are not usually connected to our communities.

Additionally, we seek support to do caregiver educational programs in multiple languages. For many South Asians – both working age adults and older adults – identifying as a caregiver and identifying the issues that come with the stress of caregiving are new and unfamiliar. As such, we request programs and funds to support caregiver education in the community setting in multiple languages.

We also ask city council to be a champion in expanding the Expanded In-home Services for the Elderly Program (EISEP). Many South Asian older adults are not Medicaid eligible and unfortunately do not qualify for a home health aide through a managed long-term care plan. As such, much of the caregiving burden falls on their family members. The EISEP program would help such families overcome their caregiving burden.

Finally, there are caregivers who care for older adults with more complex needs such as dementia or cancer. India Home is serving older adults with dementia, however, there are no specialized funding streams for caregivers who have to address such complex issues. City council and the Department for the Aging should set aside fund enhancements to specifically target those who are caregiving for more complex issues so they can be supported even more.

Thank you so much for your time and consideration. We appreciate your leadership and vision in making the city a better place to age for everyone.

Lakshman Kalasapudi
Deputy Director
India Home

jasa

**New York City Council**
**November 29, 2017**
Committee on Aging
Oversight: Supporting Unpaid Caregivers
*Remarks on behalf of JASA by Molly Krakowski, Director of Legislative Affairs*

Good morning. My name is Molly Krakowski and I am the Director of Legislative Affairs at JASA. I would like to thank Council Member Chin, and the members of the Aging Committee for holding this important hearing on providing support to New York City's unpaid caregivers, and for allowing me to submit this testimony on behalf of JASA. JASA would also like to take the opportunity to thank this Committee, the City Council leadership and the Administration for recognizing the growing needs of caregivers and adding $4 million to the FY18 budget specifically for the new Caregiving program.

JASA's mission is to sustain and enrich the lives of aging New Yorkers in their communities, enabling them to live safely at home and connect with the people, places and experiences that provide meaning. JASA's programming promotes independence, safety, wellness, community participation, and an enhanced quality of life for New York City's older adults. Our varied programs provide a continuum of care to over 40,000 clients annually. Over the past 49 years, JASA has developed a comprehensive, integrated network of services including case management, NORC supportive services, housing, licensed mental health, legal services, Adult Protective Services, advocacy, home care, senior centers, and special services for caregivers and victims of elder abuse. A critical component of our services, is the DFTA-funded Caregiver Respite Program in Brooklyn.

Through the Caregiver Respite Program in Brooklyn, JASA provides direct assistance to 200 caregivers, and reaches nearly 1,000 individuals annually, helping family caregivers with such services as in-home and group respite care, individual counseling, access to benefits and entitlements, purchases of daily care supplies, installation of home modifications to improve home safety, and peer-oriented caregiver support groups. Through educational outreach, JASA's Brooklyn Caregiver Respite Program also promotes community awareness about family-caregiver/care-recipient needs and available resources.

JASA staff helps families avoid potential crises, and conducts individualized planning for long-term care needs. It is 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.

JASA's caregiver contract with the Department for the Aging covers 14 CDs of Brooklyn, and provides funding for three BA level social workers, a program director and a part time data entry clerk. As we have presented in previous hearings, low salaries result in high turnover rates. JASA subcontracts with a home care agency to provide up to 8 hours per month of respite - the limited number of hours is due to the budget constraints. As of July 1, we pay $19.50, and this will rise again in January. There has not been a change in the DFTA contract dollars for the past 7 years.

We anticipate that the additional allocated funds for caregiver programs will help cover the higher cost of providing services, and will result in additional respite hours for clients. No more than 20% of the caregiver funding can be used for supplemental expenses, such as medical, nutritional supplies, transportation and other forms of assistance to caregivers.

We have had a number of focus groups with caregivers and care recipients to determine areas which would be supportive. Most caregivers feel socially isolated, and we want to find ways to provide services beyond respite care to give them an opportunity to make themselves valuable and reduce isolation - connecting them to the community. While we appreciate DFTA funding for respite, we also need to invest in new models specifically aimed at reducing the social isolation and emotional support.

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. One year of nursing home placement for one person is reimbursed by Medicaid at approximately $120,000 in NYS. Consider the comparison with the entire Brooklyn Caregiver Respite program of a few hundred thousand dollars, which helps keep hundreds of individuals stable in the community every year.

Caregiver programs enable 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 unpaid caregivers and an openness to proposals to fund proven programs and new initiatives.

Thank you.

Molly Krakowski
Director of Legislative Affairs, JASA
mkrakowski@jasa.org
212 273-5260

CARING ACROSS GENERATIONS
NEW YORK CARING MAJORITY

FOR THE RECORD

# New York Caring Majority: Who We Are

The New York Caring Majority is a movement of seniors, people with disabilities, family caregivers, and domestic and home care workers from all across the state. We advocate for a more sustainable and just caring economy that will help all New Yorkers who give and who receive care live fuller and healthier lives.

Our goals are:

- To make long-term care services and supports affordable and accessible to all New Yorkers who require additional support to live independently;
- To improve the quality of long-term care jobs and create the caregiving jobs we will need to meet growing demand; and
- To protect essential programs such as Medicaid, Medicare, the Older Americans Act, and the Affordable Care Act.

New York's long-term care system was straining to support our families long before the 2016 election. Now, as we face devastating cuts to our social safety net from the federal level, our local and state elected officials must step up and lead by improving and expanding the programs that our families need.

## Our Principles

### No cuts to care for New Yorkers

In this time when we are facing disastrous attacks to our social safety net, we must work together to protect our most vulnerable neighbors from losing the supports that allow them to stay healthy and live with dignity. We must stop the attacks on Medicaid, Medicare, the Older Americans Act, and the Affordable Care Act, and ensure essential medical benefits and services continue for all New Yorkers.

## Ensure universal long-term care coverage for all New Yorkers, including older adults and people with disabilities

All New Yorkers should have access to affordable and high-quality long-term care options, regardless of income. Our state government has an important role to play in covering New Yorkers who are not eligible for Medicaid and struggle to pay for the long-term care services and supports they need out of pocket.

New York already has several excellent programs that provide services to seniors and people with disabilities (e.g., the Expanded In-home Services for the Elderly Program, or EISEP). These programs provide a foundation upon which New York can build in order to expand access to affordable home care for all New Yorkers. But inadequate funding and growing waiting lists for those whose incomes are above the Medicaid threshold have left New York's seniors languishing. Developing EISEP into a statewide universal program with a dedicated revenue stream would not only improve the lives of millions of people in New York, it would also relieve the budgetary pressure from our state's Medicaid program, while also protecting against devastating cuts from the Trump administration.

## Support New York's family caregivers and invest in our direct care workforce

We must support the home care workers and family caregivers who enable New Yorkers to live at home with dignity. Expanding long-term care coverage is an opportunity to create new quality jobs in the home care and direct care sector. New York can lead the nation by investing in this fast-growing and vital workforce and by providing dedicated state revenue for workforce development and worker cooperative incubation, along with continued support for high minimum standards for wages and benefits. In many underserved areas of the state, the care workforce shortage is already at crisis levels. Supporting and expanding the workforce is a key strategy in making sure that New York can fulfill its promise for all aging residents.

## Who we are

NY Caring Majority organizations are New York's leading organizations representing seniors, family caregivers, people with disabilities, direct care workers and families struggling to juggle care for our loved ones.. Our Steering Committee Members are:

A Better Balance
Caring Across Generations
Consumer Directed Personal Assistance Association of New York State
Hand in Hand: the Domestic Employers Network
Jews for Racial and Economic Justice
LiveOn New York
National Domestic Workers Alliance
National Employment Law Project
New York Statewide Senior Action Council, Inc
PHI New York

**For more information, contact:**
Rachel McCullough
rachel@jfrej.org
www.nycaringmajority.org

# 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: IAN MAGERKURTH

Address: 60 E. 42nd St 2240

I represent: ALZHEIMERS ASSOCIATION /

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# 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: Lakshman Kalasapudi

Address: India Home

I represent: ________

Address: ________

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# 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: Molly Krakowski

Address: ________

I represent: JASA

Address: 247 W 37th St 10018

*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:* 11.29.17

**(PLEASE PRINT)**

Name: Donna Corrado, Commissioner
Address:
I represent: DFTA
Address:

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# 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: Robin Fenley, Assistant Commissioner
Address: Bureau of Health Care Connections
I represent: DFTA
Address:

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# 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: Caryn Resnick, Deputy Commissioner,
Address: External Affairs
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: 11/29/17

(PLEASE PRINT)

Name: Bobbie Sackman

Address: Jews for Racial + Economic Justice

I represent: NY Caring Majority

Address:

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# 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: 11/29/17

(PLEASE PRINT)

Name: Maggie Ornstein

Address:

I represent: The NY Caring Majority

Address: + Jews for Racial + Economic Justice

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# 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: JED LEVINE

Address: 112 W. 72 NC

I represent: CARINGKIND

Address: 360 Lexington Ave NC

*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:* ________

**(PLEASE PRINT)**

**Name:** Joshua Sidis

**Address:**

**I represent:** Mayor's office

**Address:** 253 Broadway 10th floor

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

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# 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:* 11/29/17

**(PLEASE PRINT)**

**Name:** Jane Fialko

**Address:**

**I represent:** SAGE

**Address:** 305 7th Ave NY NY 10001

***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. Caregiving Res. No.

☐ in favor ☐ in opposition

*Date:* 11/29/17

(PLEASE PRINT)

Name: Chris Widelo

Address:

I represent: AARP NY

Address: 750 3rd Ave, Manhattan

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

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# 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: Marcia Friedlander

Address:

I represent: SNAP Caregiver Program

Address:

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