

CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON AGING

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November 29, 2017
Start: 10:09 a.m.
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HELD AT: Council Chambers - City Hall

B E F O R E: MARGARET S. CHIN
Chairperson

COUNCIL MEMBERS: Karen Koslowitz
Deborah L. Rose
Chaim M. Deutsch
Mark Treyger
Paul A. Vallone
Rosie Mendez

A P P E A R A N C E S (CONTINUED)

Donna Corrado, Commissioner
New York City Department for the Aging, DFTA

Karen Resnick, Deputy Commissioner
External Affairs
New York City Department for the Aging, DFTA

Robin Finley, Assistant Commissioner
Bureau of Health Care Connections
New York City Department for the Aging, DFTA

Joshua Sidis, Senior Advisor for
Mayor's Office of Operations, MOO

Caitlin Hosey, Live On New York

Chris Widelo, NYC AARP

Jane Fialko, Care Manager, SAGE

Jed Levine, Executive Vice President & Director
Programs and Services of Caring Kind

Bobbie Sackman, Jews for Racial and Economic
Justice, New York Caring Majority Coalition

Maggie Ornstein
New York Caring Majority Coalition

Marcia Friedlander, Clinical Director
Services Now for Adult Persons Caregiver Program

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

Molly Krakowski, Director of Legislative Affairs
JASA

Lakshman Kalasapudi, Deputy Director
India Home

2 [background comments]

3 SERGEANT-AT-ARMS: Quiet, please. [gavel]

4 CHAIRPERSON CHIN: We're not starting the
5 hearing on Supporting Unpaid Caregivers. Good
6 morning.

7 COUNCIL MEMBER: [off mic] Good morning.

8 CHAIRPERSON CHIN: My name is Margaret
9 Chin, Chair of the Committee on Aging. Thank you all
10 for joining us today. Today's hearing will provide
11 the committee with an opportunity to discuss the
12 needs of unpaid caregivers, evaluate the services
13 available to caregivers and discuss how to expand
14 existing services and/or create new services in order
15 to best serve caregivers' needs. Unpaid caregivers
16 play an important role in the daily lives of care
17 recipients. Caregivers in the aging service system
18 include grandparents who care for their grandchildren
19 as well as working adults, many of whom are woman who
20 care for seniors. Many adults also provide care to
21 other adults with disabilities. The economic value
22 of this work is significant. New York State
23 Department for the Aging estimates that the economic
24 value of unpaid caregiving in New York State is \$25
25 billion. The Committee has previously discussed

2 issues relate to unpaid caregivers this session,
3 which led to the passage of Local Law 97 of 2016.
4 Local Law 97 require the Department for the Aging,
5 DFTA ,to survey the unpaid caregivers' population in
6 New York City to gain a better understanding of
7 demographics of the population, the services that
8 caregivers need and the barriers to services that
9 caregivers face. Local Law 97 also required DFTA to
10 create a comprehensive plan to address the needs of
11 unpaid caregiving—caregivers based on the results of
12 the survey. In addition, in the Fiscal Year 2018,
13 the Year of the Senior, a budget of \$4 million was
14 baselined for city funded caregiver program. Today,
15 we will hear from DFTA and the Administration
16 regarding the results of survey and the FY2018
17 Caregivers Budget item. We will also hear from
18 providers and advocates in order for the Committee to
19 explore ways that the city can increase caregivers'
20 awareness and participation in available services,
21 expand existing services for caregivers and care
22 recipients and create new services to assist unpaid
23 caregivers and care recipients. I would like to
24 thank the staff of the Committee on Aging for their
25 assistance in putting together this hearing, our

1 COMMITTEE ON AGING

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2 Counsel Caitlin Fahey, Policy Analyst Emily Rooney,
3 and Finance Analyst Daniel Coop. I also would like
4 to thank the members of the committee that have
5 joined us here today: Council Member Vallone, Chair
6 of our Subcommittee on Senior Centers; Council Member
7 Koslowitz from Queens, Council Member Deutsch from
8 Brooklyn and Council Member Treyger from Brooklyn. I
9 would like to invite up the first panel, our
10 Commissioner Donna Corrado, Robin Findley, the
11 Assistant Commissioner is—oh, Carolyn Resnick is
12 Deputy Commissioner for External Affairs of DFTA, and
13 also Joshua Sidis from the Mayor's Office of
14 Operations. Our Counsel will swear you in.

15 LEGAL COUNSEL: Can you raise your right
16 hand. Do you affirm to tell the truth, the whole
17 truth, and nothing but the truth in your testimony
18 before this committee, and to respond honestly to
19 Council Member questions?

20 COMMISSIONER DONNA CORRADO: I do.

21 LEGAL COUNSEL: Thanks.

22 COMMISSIONER DONNA CORRADO: Good morning
23 Chairperson Chin, members of the Aging Committee, my
24 colleagues, caregivers and friends of the Aging
25 Committee. I'm Donna Corrado, Commissioner of the

2 New York City Department for the Aging, and as the
3 Chair had mentioned, I'm joined here by Karen Resnick
4 our Deputy Commissioner for External Affairs; Robin
5 Finley, Assistant Commissioner of the Bureau of
6 Health Care Connections at DFTA; and Joshua Sidis,
7 the Senior Advisor for the Mayor's Office of
8 Operations. Thank you for the opportunity to discuss
9 supporting unpaid informal caregivers. Millions of
10 people throughout the United States are informal
11 caregivers. More than 44 million individuals provide
12 care for both biological and chosen family members
13 who are chronically ill, disabled, or aging. These
14 caregivers assist with running errands, paying bills,
15 preparing meals, picking up and administering
16 medications, helping with activities of daily living
17 such as bathing, dressing and more. In New York
18 State there are approximately 1.9 million caregivers.
19 Approximately 1.3 million individuals served as
20 informal caregivers in New York City recognizing that
21 this number could, in fact, be much larger, and that
22 people often do not recognize—recognize that they are
23 caregivers. Nationally, the average time spent in
24 providing care is more than 24 hours per week, which
25 is essentially a second job for many caregivers.

2 Nearly 1 in 4 caregivers in the U.S. spends 41 hours
3 or more a week providing care. The economic value of
4 these informal unpaid caregivers throughout the
5 country is estimated to be \$470 billion a year.
6 Women comprise 60%--66% of caregivers in the United
7 States, and 2.5 times more likely than non-caregivers
8 to be—to live in poverty and coping with these
9 combined pressures of caring for a loved one, their
10 needs for income, reliance on public assistance, and
11 fewer—and fewer employment related benefits. In
12 addition, 2.7 million grandparents in the U.S. serve
13 as the primary caregiver for their grandchildren.
14 More than half of these grandparents or 55% have been
15 serving as primary caregivers for three years or more
16 and 38% have been doing so for five years or more,
17 one-fifth or 22% of grandparent caregivers are living
18 below the poverty line while 10% among the general
19 population of individuals 50 and older are below the
20 federal poverty line. In New York City about 66,000
21 grandparents are raising grandchildren under the age
22 of 18. As you know, DFTA was charged in August of
23 2016 with conducting a citywide survey of caregivers
24 in an effort to gain a better understanding of the
25 needs of 1.3 million caregivers in New York City.

2 The 2017 survey of informal caregivers came together
3 through the collaborative efforts of government
4 entities, DFTA, the Mayor's Office of Operations, the
5 Administration for Children's Services, the Mayor's
6 Office of People with Disabilities, the New York
7 State Office of People with Developmental
8 Disabilities, DFTA and the Mayor's Office of
9 Operations together formed a coalition of various
10 experts from Social Service agencies throughout this
11 process to help shape and implement the survey. In
12 addition, the survey included AARP caregivers who are
13 not known to be affiliated with government or the
14 provider networks. Westat a nationally known social
15 service research company, conducted the survey and
16 provided the preliminary analysis. Survey results
17 were based on the participation of more than 2,000
18 New York City caregivers. DFTA has been working
19 closely with the Mayor's Office of Operations in
20 analyzing and mining the survey data, which will
21 guide the city's response to the growing need of
22 caregivers. The Mayor's Office of Operations will
23 delve into the survey findings in their testimony
24 this morning. DFTA has contracted with community-
25 based organizations citywide since 2001 to provide

2 services under the National Family Caregiver Support
3 Program. National Family Caregiver Support Program
4 currently funded at \$8 million in Fiscal Year 18.

5 DFTA's ten caregivers programs have served more than
6 6,200 individuals throughout the city in the last
7 fiscal year, Fiscal Year 17. We provided information
8 about caregiving, and discussing the associated
9 stresses and offering pertinent resources such as
10 respite and supplemental services. Also available
11 for caregivers through these programs is supportive
12 counseling, support groups and training. Seven of
13 the ten DFTA sponsored caregiver programs served
14 designated catchment areas. Of these seven programs,
15 three served grandparents raising grandchildren in
16 addition to working with adults, child and spousal
17 caregivers. The remaining—remaining three programs
18 assist caregivers citywide. One program serves
19 Chinese, Japanese and Korean caregivers. Another
20 program serves the blind and visually impaired, and
21 the third serves the LGBT caregiver community. In
22 terms of language access, caregiver services are
23 provided to individuals who speak Spanish, Russian,
24 Polish, Ukranian, Filippino, Greek, Mandarin,
25 Cantonese, Korean, and Japanese, and Language Line is

2 available for other languages or dialects. As you
3 know, the current funding level of \$8 million for
4 caregiver programs includes the additional \$4 million
5 that was baselined in Fiscal Year 18 to support
6 caregivers. This was a major investment by the
7 Administration, which doubles DFTA's existing federal
8 allocation for caregiver services, and as a result of
9 this enhanced funding, based on Fiscal 17 service
10 levels, we anticipate that in Fiscal Year—that by
11 Fiscal Year 19 we will double the number of
12 caregivers receiving individual home care and group
13 adult day Respite Services. We will triple the
14 number of caregivers utilizing overnight or other
15 respites for their care receivers who will—who will
16 benefit from these services. The number of
17 caregivers receiving supplemental services will
18 increase by 25%. This new caregiver funding is
19 intended to provide support to the caregiver and care
20 receiver with the creative flexibility that they need
21 to access services while ensuring the quality of care
22 by the selected service provider. Existing caregiver
23 program contracts will be amended to include this
24 funding. To clarify outreach efforts and illustrate
25 how individuals are identified as caregivers and

2 subsequently connected to services, DFTA caregiver
3 programs canvass neighborhoods with flyers
4 advertising their services. They write articles on
5 caregiving for local papers. They appear on radio
6 and television to discuss caregiving issues, and they
7 conduct free information sessions on a variety of
8 caregiver related topics such as memory loss,
9 alternative residential options, and community
10 resources. Caregiver assistance is also available
11 through DFTA's Caregiver Resource Center. In Fiscal
12 Year 17, more than 3,500 individuals received
13 information and referrals regarding residential
14 alternatives, long-term care services and supports
15 and appropriate community services. Case
16 consultation is provided to professionals also that
17 are seeking services and need to know more about
18 what's available. The Caregiver Resource Center like
19 many DFTA units conduct outreach by way of
20 participation on panels or other public speaking
21 opportunities providing year another caregiver for
22 self-recognition. In addition, an increasingly
23 social media has been utilized so that seniors can
24 identify-self-identify as caregivers and reach out to
25 the Caregiver Resource Center and also to New York

2 Connects. We will—we established the New York
3 Connects recently as the Aging and Disabilities
4 Resource Center through New York City, and this has
5 been a tremendous asset and a way for us—and a
6 vehicle for us to identify caregivers, and—and guide
7 them to the necessary Caregiver Resource Center and—
8 and whatever supports are available we're able to
9 link them up. In addition the Caregiver Resource
10 Center provides contract oversight to the ten
11 contracted programs ensuring compliance with meeting
12 the expectations of the National Family Caregiver
13 Support Program and its DFTA's contract. These
14 programs meet monthly for administrative updates,
15 case discussion and problem solving, and information
16 sharing on pertinent—and—on pertinent events as well
17 as presentations by experts who provide additional
18 resources for caregiver clients. Years ago, DFTA
19 recognized that an increasing number of the city's
20 older adults were caring for grandchildren or other
21 young relatives, and responded with programs to
22 support them. The Grandparent Resource Center. The
23 first of its kind in the nation, was established by
24 DFTA in 1994. The Grandparent Resource Center
25 provides a number of supportive services to those

2 adults who are raising grandchildren and other young
3 relatives. Resource specialists at the GRC offer
4 advocacy and case assistance as well as referrals to
5 appropriate community-based organizations. These
6 community-based providers provide services such as
7 prevention, legal services, financial assistance,
8 advocacy, education, tutoring—tutoring for children,
9 family counsel, and support groups. The Grandparent
10 Resource Center has worked to provide information and
11 referrals, case assistance and trainings. Working
12 with community partners, the GR—the GRC, Grandparent
13 Resource Center, organizes educational forum—forums
14 and events for grandparent caregiving, the
15 grandparent caregiving community. The—the Resource
16 Center presentations and training for caregivers are
17 held at local schools, hospitals, churches, and other
18 religious institutions. In Fiscal Year 17, there
19 were more than 500 grandparent caregivers served.
20 Through the Resource Center more than 2,600 service
21 units were provided including case assistance,
22 counseling, information, training and support group
23 participation. In order to serve some of the
24 neediest kinship caregiver families, the Resource
25 Center program expanded in Fiscal Year 15 under the

2 Mayor's Action Plan for Neighborhood Safety, or MAP,
3 and the GRC received an additional \$472,000 since
4 Fiscal Year 15 for the DFTA community advocates to
5 work with residents of the 15 New York City housing
6 developments and provide resources and services to
7 grandparent caregivers. Through this initiative,
8 grandparents and relative caregivers have received
9 grandparenting education, training, intergenerational
10 program and peer support on how to raise their
11 grandchildren. Thank you again for this opportunity
12 to provide testimony on supporting unpaid informal
13 caregivers. We have only begun to scratch the
14 surface in understanding the breadth of the needs of
15 our informal, unpaid caregivers, and how best to
16 respond while preserving the uniqueness of each
17 individual's approach to caring. Local Law 97
18 provided the opportunity to address this. If there
19 is one overarching takeaway from the 2017 Survey of
20 Informal Unpaid Caregivers in New York City, it is
21 the similarity of need regardless of who is providing
22 that care. Following the testimony by the Mayor's
23 Office of Operations, I will be available along with
24 my colleagues to answer questions. Thank you.

2 JOSHUA SIDIS: Thank you, Commissioner.

3 Good morning, Chairwoman Chin and members of the
4 Committee on Aging. I am Joshua Sidis, Senior
5 Advisor for the Mayor's Office of Operations. I'm—
6 I've been closely involved in the creation and
7 delivery of the Survey of Unpaid Caregivers in New
8 York City, as well as the Report on Unpaid Caregiving
9 released this fall. I alongside Commissioner Corrado
10 am also coordinating the effort to draft
11 recommendations and a comprehensive plan required by
12 Local Law 97, which will be delivered to the City
13 Council by the end of the year. Thank you for the
14 opportunity to speak today about the efforts taken to
15 understand the unpaid caregiving community in New
16 York City and for your attention to this important
17 issue. The Mayor's Office of Operations first became
18 involved in this initiative because the office has
19 experienced guiding complex projects on tight
20 timelines. As Ops, quickly learned, the effort also
21 became a natural fit as it involved an intense amount
22 of interagency work, and external coordination. As
23 many in this room can attest, this project was a
24 tremendous effort that included strategic
25 development, research and expertise. While a year

2 goes by quickly, those involved in this work
3 accomplished a lot in a short amount of time. The
4 survey was created using insight from DFTA, the
5 Mayor's Office Economic Opportunity, the
6 Administration for Children's Services, the Mayor's
7 Office of People with Disabilities, the New York
8 State Office for People with Developmental
9 Disabilities, and AARP, as well as external
10 stakeholders and providers. The city partnered with
11 Westat, an external research firm to develop a survey
12 that met high standards for statistical analysis.
13 Their surveys were available in several languages:
14 Russian, Korean, Chinese and Spanish, and large text
15 options were available for the vision impaired. The
16 study divided the unpaid caregiver population into
17 three primary groups. Each was provided a similar
18 but specialized survey tailored to their experiences.
19 The three groups were: Adults caring for family
20 members of the age of 60 including those with
21 Alzheimer's—including those with Alzheimer's Disease
22 or other dementia; grandparents or other relatives
23 who are the primary caregivers of children under 18;
24 and adults caring for individuals with disabilities
25 between the ages of 19 and 59. Alzheimer's and other

2 dementia was not broken out into its own group
3 because although these are unique problems, many of
4 these services—and many of the services and funding
5 sources for helping these populations overlap
6 significantly with others—others for adult—for older
7 adults. Additionally, it is difficult to distinctly
8 disaggregate people with dementia from those without.
9 Caregivers of people with memory loss may not always
10 acknowledge that the person they care for has a
11 problem attributing their behavior—behavior to old
12 age rather than an illness. NYC Opportunity and
13 Westat conducted the survey after first collecting
14 ample demographic information about all caregiver
15 groups to assure there was a diverse field of
16 participants. After identifying groups of
17 participants including, but not limited to ACS foster
18 parents, participants in DFTA programs and AARP
19 members who identified themselves as caregivers,
20 random samples of each subset were taken and surveys
21 were mailed or emailed to caregivers. The survey
22 also noted a point of contact at each agency for
23 questions or help. Due to the nature of the survey
24 audience, most surveys were mailed via standard post.
25 Each survey was designed to take about 30 minutes to

2 complete and response rates ranged from 10 to 30% for
3 each group. These response rates are noteworthy
4 given the survey's depth and distribution methods and
5 length. All surveys addressed two primary questions:
6 To what extent are unpaid caregivers able to obtain
7 the services they need, and what barriers do unpaid
8 caregivers continue to face when they do obtain those
9 services. To study those collected demographics—to
10 study also collected demographic information about
11 the unpaid caregiver population and their burden.
12 Information about areas of need were recorded as
13 well. The offices prepared a presentation that
14 summarizes the survey's top line results, which will—
15 which will be discussed now. The deck will be
16 entered into the record for this hearing. So, there
17 are several slides here. I will try to move through
18 this so it is not nap inducing. So, bear with me.
19 Just starting at the top here one thing that we want
20 to note is the order of magnitude that we're talking
21 about with caregivers. We estimated about 900,000 to
22 1.3 million caregivers in New York City. We also
23 want to note that this is likely a conservative
24 estimate, as caregiving is not a one-to-one.
25 Sometimes there are multiple caregivers to care

2 recipients, and sometimes one care recipient serves-
3 sorry-is served by multiple caregivers or vice versa.

4 I want to note that the survey reached out to
5 approximately 18,000 New Yorkers who identified
6 themselves as caregivers, and what we found was in
7 large part caregivers are women. Depending on the
8 survey group it ranged from 60% to 80% were women,
9 and largely they were over the age of 50. More than
10 half of the caregivers provided more than 30 hours of
11 care per week. Two of the most prevalent barriers to
12 obtaining services were lack of knowledge regarding
13 available services and income financial limitations.
14 At least one-third of each caregiver group struggled
15 financially. The button. There we go. So, digging
16 into a little bit of the demographic information for
17 the three caregiver groups we're going to start with
18 adults with disabilities. So, again, most of the
19 respondents were women here. You can see it's 84%
20 who responded were women. Most were non-white at 60%
21 and again, most respondents were over the age of 50.
22 Going over to-English was the primary language of
23 those who responded. Moving into the kinship
24 caregivers, so in the kinship caregivers we reached
25 out to ACS foster care parents as well as Grandparent

2 Resource Center grandparents from DFTA's Grandparent
3 Resource Center. Again, we see largely a female—the
4 respondents were largely female, and the majority of
5 both groups were women, African-American, and list
6 English as their primary language as noted before,
7 and DFTA caregivers were more likely to be over the
8 age of 65. For the older adults, we'll see here
9 split between DFTA's Older Adult program and the AARP
10 Older Adult Program. This is where the age range is
11 between 60 and 80%. DFTA's respondent's 30% were
12 white non-Hispanic, 31% were black, 21% were
13 Hispanic. So, moving into a bit of a—the service
14 needs—moving into the service needs, we see that
15 caregivers reported meeting for—this is adults with
16 disabilities. Caregivers reported meeting but not
17 receiving respite care and information about
18 available services. As the Commissioner noted, these
19 were things that—they were common themes across all
20 of the caregiver groups that we'll see over and over
21 again, and these two tend to stand out. So, again,
22 this is for kinship caregivers' service needs.
23 Counseling was one that stood out. Respite care also
24 stands out, but we can also see a need that's
25 comparable: Legal services, information about

2 available services and support group services are a
3 also.

4 CHAIRPERSON CHIN: Can we just--can we ask
5 you questions along the way?

6 JOSHUA SIDIS: I thought that might be a
7 question. I--it seems--it seems fair. Why not?

8 CHAIRPERSON CHIN: So we don't--

9 COUNCIL MEMBER VALLONE: Just as you're
10 going along.

11 JOSHUA SIDIS: No, of course, of course.

12 COUNCIL MEMBER VALLONE: Certain things.

13 JOSHUA SIDIS: It seems fair, yeah. Just
14 quickly--

15 CHAIRPERSON CHIN: [interposing] So,
16 Council Member Vallone has a--

17 JOSHUA SIDIS: You want me to go back?

18 COUNCIL MEMBER VALLONE: No, just since
19 we're talking about a survey, let's start with who-
20 who was surveyed? How many people were surveyed and
21 who was reached out to? Because I'm already at odds
22 with the numbers Jerry started with.

23 JOSHUA SIDIS: 18,000 people were reached
24 out to. We got over 2,000 respondents.

1 COMMITTEE ON AGING

23

2 COUNCIL MEMBER VALLONE: And where were
3 the 18,000 people located?

4 JOSHUA SIDIS: So, it's a combination of
5 DFTA. We used DFTA, Grandparent Resource Center,
6 older adults on the DFTA rolls, AARP was another pool
7 that we reached out to, ACS foster parents was
8 another group that we reached out to. Did I miss
9 any?

10 COMMISSIONER DONNA CORRADO: Disability.

11 JOSHUA SIDIS: And disability. OPWDD and
12 MOPD.

13 COUNCIL MEMBER VALLONE: So, was data
14 contained within those organizations?

15 JOSHUA SIDIS: Correct.

16 COUNCIL MEMBER VALLONE: Is it broken
17 down by borough or was it just by numbers?

18 JOSHUA SIDIS: It was not—it was broken
19 down by borough. Was that the question?

20 COUNCIL MEMBER VALLONE: No, no because
21 that's where my issue is.

22 JOSHUA SIDIS: Okay.

23 COUNCIL MEMBER VALLONE: So, we'll talk
24 about that later.

25 JOSHUA SIDIS: Sure.

2 COUNCIL MEMBER VALLONE: But these—these—
3 these clearly do not reflect numbers throughout the
4 rest of the city because I would be at odds with some
5 of the statistics on who's providing. I think
6 everyone is providing adult care services. I don't
7 think it's based on minority, race, age, color or
8 anything. I think it's across the board. The entire
9 city is faced with this situation not just you.

10 JOSHUA SIDIS: I completely agree,
11 completely agree with that.

12 COUNCIL MEMBER VALLONE: Alright, so
13 we'll let you keep going.

14 COMMISSIONER DONNA CORRADO: No, but that
15 was just the demographic breakdown that he was
16 referring to.

17 JOSHUA SIDIS: That was the demographic
18 breakdown of the survey respondents.

19 COUNCIL MEMBER VALLONE: Alright, we'll—
20 we'll continue.

21 JOSHUA SIDIS: Yeah. Where were we?
22 Older adult caregiver service needs. So, for the
23 kinship caregivers, DFTA and ACS caregivers were both
24 likely to need and not receive respite care, and
25 information about available services. For older

2 adults, again we see respite care as a—as a need
3 that—a service need that was not received, and then
4 there are also significant levels of need for
5 information. Again, information legal services and
6 counseling as well. Caregivers for older adults with
7 disabilities. We can see here this is about
8 satisfaction with the caregiver services. We see
9 that in large part when folks do receive the services
10 they are, in fact, satisfied with the services that
11 they received with—with a couple of exceptions. We
12 see respite care towards the bottom there and support
13 groups. For kinship caregivers, satisfaction with
14 caregiver services. We—we seen kinship caregivers
15 are generally satisfied also especially with support
16 groups and counseling. Some of the areas that we're
17 highlighting here are the areas of need that are
18 lower on the percentage points. Their help obtaining
19 them and benefits as well as information about
20 available services. Alright. Older adults, older
21 adult caregivers, this is satisfaction with caregiver
22 services. Again, here we see in large part generally
23 satisfied, but we do see respite care standing out as
24 a distinct need, as an area where the satisfaction
25 is—is lower. I don't know if there's any co-effect.

2 For caregivers for older adults with disabilities,
3 care recipient service needs. So, this is about the
4 care recipient. I just want to be clear about that.
5 We see again here for people they care for,
6 caregivers were likely to need and not receive a
7 number of services: Housing support, home care,
8 networking and information about available services.
9 Again, information about available services is up
10 there again. For kinship caregivers care recipient
11 service needs. So this is for the minors they care
12 for. DFTA and ACS kinship caregivers were likely to
13 need and not receive childcare, but for DFTA, for the
14 Grandparent Resource Center, there were a few more
15 care recipient needs, education assistance or
16 advocacy. Housing and transportation were also
17 called out. For care recipient service needs for
18 older adults, again we see a number of needs and
19 again this is for care recipients. We see social
20 activities, information, home care, and
21 transportation are all called out equally across the
22 board. Any questions? I know I'm breezing through
23 this. Are there any? We're good? Okay. Good. So,
24 caregivers with—caregivers with—caregivers for older
25 adults with disabilities their satisfaction with the

2 care recipient for the—the care the care recipient
3 received. We see low on the list here home care and
4 transportation again stand out. These are—these are
5 needs. These are—these are areas where we can
6 improve. Kinship caregiver satisfaction with care
7 recipient services. Again, we see transportation pop
8 up. This is for kinship caregivers for the GRC
9 group. For the ACS foster parents, we see both
10 counseling and transportation. For older adult
11 caregivers, satisfaction with care recipient
12 services, we see for the DFTA group a need in home
13 care, and a need in housing services as well. With
14 the AARP group a need in homecare as well. So, this
15 is caregivers for adults with disabilities barriers
16 to service. So, you see the—the left column is the
17 service. The top column is the—the barriers into—the
18 top row, rather is the barriers to that service. We
19 see respite care stands out for both don't know if
20 the service is available, financial issues and then a
21 long waitlist as well. Counseling is another area
22 that we want to highlight for not knowing if the
23 service was available. Moving on. So kinship
24 caregivers' barriers to service. We broke this out
25 for the GRC caregivers as well as the ACS and—and to

2 the bigger tables. Again, another theme here is
3 information about the service for both categories and
4 then financial issues pop up for legal services for
5 both categories and then a waitlist for housing for
6 the GRC group. So, for older adults, barriers to
7 service, splitting up the groups again for the DFTA
8 caregivers and the AARP caregivers we see across the
9 board a need for all services and not knowing that
10 the service was available. This is again a common
11 theme here. Information about the service is
12 important. It's something that we just want to
13 highlight for you all today. And then this last
14 section is—is about employment and income security,
15 and so for adults with disabilities, the majority of
16 caregivers are employed full or part-time. Most do
17 say that caregiving does affect their job in some
18 way, and almost half report barely managing to get
19 by, or say they cannot make ends meet, and this is
20 another one that we see about a third across the
21 board, a third of every group says this. Some it's
22 more acute in some groups than others. Kinship
23 caregivers again GRC caregivers are more likely to be
24 retired and the majority 62% bare—report barely
25 managing to get by with an additional 9% that cannot

2 make ends meet. I want to— I want to pause here for
3 a second and—and denote a difference that we're going
4 to see is ACS foster parents—foster parents receive a
5 stipend, but I think that this—this plays out and we
6 can see this in the—if we drop all the way down to
7 the cannot make ends meet and barely manage to get
8 by, we see the difference between the GRC kinship
9 caregivers and the ACS kinship caregivers. So, just
10 looking at—at what that little bit of extra money can
11 do for folks, I think really stood out. And then
12 lastly, older adult caregiver's employment and income
13 security again kind of the same story—story. Nearly
14 half of the survey respondents are retired. Of those
15 who are employed, many say that caregiving affected
16 their employment. We see that 51% of DFTA and 47% of
17 caregiver, AARP caregivers report barely managing—
18 barely being able to get by or cannot make ends meet.
19 So, a similar tale across all three groups. Since
20 releasing the report, operations has convened a
21 working group co-chaired by DFTA. The working group
22 includes experts from ACS, MOPD the Department of
23 Education, AARP, Health and Hospitals, the Commission
24 on Gender Equity, the Office of Management and
25 Budget, and the City Council among others. The full

2 working group is divided into four subcommittees:
3 Communications, Policy, Services and Economic
4 Stability with the goal of creating recommendations
5 that address the areas of greatest need identified by
6 the survey. The process is well under way. Thank
7 you Chairwoman Chin for taking the time to speak with
8 us today. I look forward to answering your
9 questions.

10 CHAIRPERSON CHIN: [pause] Alright,
11 we're going to have some questions, and I'll—I'll
12 start with Council Member Vallone. [laughter] I'll
13 let you go first.

14 COUNCIL MEMBER VALLONE: That'll teach
15 you well.

16 CHAIRPERSON CHIN: And then followed by--
17 other Council Members have questions, too, so--

18 COUNCIL MEMBER VALLONE: Just the last
19 thing you said there was a working group that
20 included the City Council.

21 JOSHUA SIDIS: Yes.

22 COUNCIL MEMBER VALLONE: Nobody up here
23 was on that. So, how do we have a working group with
24 a hearing and the City Council and the Chair of a

2 senior center and a chair of Aging, and not be part
3 of that?

4 JOSHUA SIDIS: So, we are working
5 actually closely with Committee Counsel as well as--

6 COUNCIL MEMBER VALLONE: [interposing]
7 From the beginning?

8 JOSHUA SIDIS: From the beginning of this
9 process. Yes, for well over a year now we've been
10 deeply involved working closely with the Committee
11 Counsel. Before the survey went out, we sent the
12 surveys over for review when it was a different
13 committee counsel, and when the results came back, we
14 did preliminary result conversations to update along
15 the way. The Council has been a part of this every
16 step of the way.

17 COUNCIL MEMBER VALLONE: I would beg to
18 differ because if we were, we wouldn't be having this
19 sentence or conversation whether the services are
20 part of a particular staff member. The Council
21 members who run the committees need to be part of
22 this, and so we need to change that going forward.
23 All of this data was information that the Chair and I
24 could have given you without doing a survey.
25 Information throughout the city. People aren't aware

2 of the services clearly, and that's in every one of
3 the categories. So, what's the next step?

4 JOSHUA SIDIS: So, the next step is--

5 COUNCIL MEMBER VALLONE: [interposing]
6 Besides including us. Then after that?

7 JOSHUA SIDIS: Yeah, I will leave it to
8 Council staff to coordinate appropriately, but when--
9 so we are working on recommendations. Again, Council
10 is deeply involved in that, and we hope to have
11 those, and we are--the others that we noted are also
12 stakeholders and providers, folks who do this,
13 deliver these services everyday, and so that--they are
14 part of the conversation. We are working through
15 recommendations, and we hope to have those done by--we
16 will have those done by the end of the year.

17 COUNCIL MEMBER VALLONE: What will be
18 done by the end of the year, conversations?

19 JOSHUA SIDIS: Recommendations?

20 COUNCIL MEMBER VALLONE: [interposing]
21 Talking about steps to-- In the data that you
22 started off with it's 1.3 million of 8.2 million New
23 Yorkers--

24 JOSHUA SIDIS: Uh-hm.

2 COUNCIL MEMBER VALLONE: --are affected
3 and 6,200 of the individuals--

4 JOSHUA SIDIS: [interposing] Uh-hm.

5 COUNCIL MEMBER VALLONE: --have been
6 through the Resource Centers. 6,200 really--6,200
7 versus 1.3 million versus 8.2 is--is not doing the
8 job. So, what are we going to do about it?

9 JOSHUA SIDIS: We are--

10 COUNCIL MEMBER VALLONE: [interposing]
11 Does everyone of us have a district or infiltrated
12 with seniors? My largest has the largest along with
13 Queens in general. Haven't seen one week's paying
14 for it, meeting or anything come out to Northeast
15 Queens. I have Queens County with Melinda Katz and
16 Karen Koslowitz is our Chair. I need to get and each
17 one of us needs to type a list ten years ago, and I'm
18 not just--so, we need to really focus on--

19 COMMISSIONER DONNA CORRADO:
20 [interposing] Can I explain this.

21 COUNCIL MEMBER VALLONE: --getting this
22 resource center up and moving, getting to the people
23 that we are, and I'll just give as a backdrop, I've
24 been doing elder law as an attorney for 25 years.
25 Not one person has walked into my office over 85

2 years or three generations and said oh, we're aware
3 of our city service. They're--they're at odds end.
4 They do not have the financial ability. They're
5 taking care of a loved one, a mother, a father, a
6 wife, a son, a child with a disability. They do not
7 have--the city does not have that person's back.
8 They're looking for Medicaid resources that are being
9 cut everyday, and some type of assistance, and then
10 the last resource is to come to a lawyer to say what
11 can we do about it. And we try to help them, but I
12 would think there are some other allies like the Bar
13 Association, student law groups--

14 JOSHUA SIDIS: [interposing] Yep.

15 COUNCIL MEMBER VALLONE: --that are
16 providing these resources that have not been
17 contacted, but need to be part of this process to
18 take this--what our chair started last year, which is
19 the Year of the Senior, which is every year--

20 JOSHUA SIDIS: [interposing] Yep.

21 COUNCIL MEMBER VALLONE: --and create
22 going forward so that we can tackle these when they
23 need it.

24 JOSHUA SIDIS: [interposing] Absolutely.

2 COUNCIL MEMBER VALLONE: So, Commissioner
3 Corrado, we are--when you're--you're--you missed the
4 test--

5 COMMISSIONER DONNA CORRADO: No, no, I
6 just.

7 COUNCIL MEMBER VALLONE: --but you gave us
8 some of the facts about the numbers--

9 COMMISSIONER DONNA CORRADO:
10 [interposing] I gave--

11 COUNCIL MEMBER VALLONE: --and the
12 people.

13 COMMISSIONER DONNA CORRADO: I did.

14 COUNCIL MEMBER VALLONE: So, I mean
15 what's your vision--

16 COMMISSIONER DONNA CORRADO:
17 [interposing] I did--

18 COUNCIL MEMBER VALLONE: --I guess for
19 this year to--to expand the Resource Center and get
20 these through it?

21 COMMISSIONER DONNA CORRADO:
22 [interposing] Right. So, in all due respect, the
23 nature of this hearing was to really speak of the
24 methodology of a survey that we did and we conducted
25 throughout this year with some professional help from

2 Westat, which is a research group, and working with
3 the Mayor's Office and our researchers here at the
4 Department for the Aging. We're basically giving you
5 the results of the study. When we first initially
6 said that, you know, the Local Law passed that we
7 were to do the study, we kind of all chuckled and
8 said, you know, we already know what's needed. We
9 know that intuitively because we've been doing this
10 work for so many years, and this was an opportunity
11 for us, and I had to step back and really think about
12 it along with my colleagues to say okay, we have a
13 year to conduct a study and have the empirical data
14 and the research behind what it is that we already
15 know. So, that's what we were reporting on, and the-
16 while the methodology is never perfect, it was an
17 intensive effort around getting and documenting what
18 the needs are of unpaid caregivers in New York City.
19 So, in all due respect we're doing a tremendous
20 amount of work over the past year analyzing the
21 study. We made sure that the methodology encompassed
22 everyone in all of the five boroughs in the best way
23 that we can, and research study has limitations, of
24 course. So, now we're analyzing this and we will
25 come up with recommendations in short order for the

2 end of the year, and with that is a process around
3 allocating funds to developing some programs. So, we
4 really want to take the time to make sure that what
5 we're doing is really going to have a significant
6 impact. Now, the \$4 million that was added to this
7 year's budget is going to make a tremendous
8 difference on what it is that the department can
9 provide and the city can provide in terms of
10 supporting caregivers. Now, we do that, right? We
11 do that now. We've been doing it for—since 1994 at
12 the department, and we will continue to grow those
13 programs, but how can we do it in a way that's really
14 meeting a targeted need that we have the research to
15 back up what those needs actually are? So, it's all
16 good, and no one would ever question that this is
17 just the beginning of a need that's only going to
18 grow in the future because caregivers. As you know,
19 as people age and people live longer, the needs are
20 tremendous, and this has not only an economic impact,
21 it has a social impact, it has a significant impact
22 on our workforce, and there's a number of challenges
23 that we need to address going forward. So this is
24 just the beginning, and just realizing that, you
25 know, we're talking about a research study and what

2 the results of those--that research was, and how we're
3 going to go forward in the future, and this will
4 inform any direction that we go in.

5 COUNCIL MEMBER VALLONE: Well, I think
6 Chair Chin and I would--would definitely say you were
7 under-funded and need twice the budget to get what
8 you need done, and this is one of those areas where
9 if you had the funding, I'm sure we wouldn't even
10 have this hearing because we could get it done. I
11 mean we understand that.

12 COMMISSIONER DONNA CORRADO: Uh-hm.

13 COUNCIL MEMBER VALLONE: Unfortunately,
14 some of our frustration and/or anger comes through
15 that we know what needs to be done. We just have to
16 get it done, and to get it done, you need the money.
17 So, I think this is the battle where we want to take
18 with you coming up with January around the corner--

19 COMMISSIONER DONNA CORRADO: Uh-hm.

20 COUNCIL MEMBER VALLONE: --and--and with
21 the--now we know who's in office, and who's--what's
22 going on that we want to be able to champion these
23 things. Because this study is basically telling us
24 what we already knew.

25 COMMISSIONER DONNA CORRADO: Right.

2 COUNCIL MEMBER VALLONE: A lot of
3 information, transportation issues, different
4 demographic issues, and there's a--there's a suffering
5 unknown population that doesn't go to a community
6 board hearing, that doesn't come here, that stays at
7 home and takes care of their loved ones silently
8 suffering without any help, and that person will
9 never show up on these, but I'll turn it over to
10 Chair Chin because I know she has some questions.

11 CHAIRPERSON CHIN: Yes.

12 COMMISSIONER DONNA CORRADO: Uh-hm.

13 CHAIRPERSON CHIN: I agree with you
14 commissioner. I mean it's just that the survey
15 confirmed a lot of what we already know because in
16 your testimony you talk a lot about, you know,
17 respite care, and that's what we were talking about
18 that we were very, you know, happy that the \$4
19 million was baselined, was put in and was baselined,
20 and it's terrific because there has never been a
21 funding stream for caregivers. I mean the money that
22 was in the budget was from the federal government and
23 the City has never put any money in except for the--
24 the Grandparent Caregiver Initiative that the Mayor
25 did for public housing residents. So, this is really

2 a good beginning, and I hope that using the result of
3 the survey that we could start implementing a lot of
4 these programs to really help support the—the
5 informal caregivers. But in the survey it looked
6 like there were. Because I was a little surprised by
7 that the primary language was English. That—my
8 questions is that, you know, you have a large
9 immigrant population that might not have been
10 included because in our district, in my district I'm
11 sure in other districts where grandparents are taking
12 care of grandchildren, and they don't speak English
13 well, and that could not be their primary language in
14 terms of accessing resources. So, the issue is still
15 letting people know what's available, and even
16 looking at the—the survey results when people talk
17 about transportation. So, much complaints about
18 Access-A-Ride, and the other thing about respite care
19 people don't even know that these kinds of programs
20 exist, or if they do it's very, very limited, and
21 homecare we've been fighting, you know, to get rid of
22 the waiting list for a long time. So, people are on
23 waiting lists, and those are the services that could
24 help the caregivers. At the same time, what we voted
25 on earlier is this whole social adult daycare

2 programs that are popping up that's supposed to help
3 caregivers and for their families, but is not. I
4 mean a lot of them are not serving the population
5 they're intended. So, I mean these--this is what's out
6 there, and so we really need to sort of put in
7 additional resources. So, I hope going forward that
8 we're not going to be just satisfied with the \$4
9 million baseline. That is just the beginning. So,
10 we hope that that funding will continue to grow, and
11 in your testimony maybe you can explain a little bit
12 more about how that \$4 million is going to be spent,
13 and then how do you see growing that budget?

14 COMMISSIONER DONNA CORRADO: Well, the
15 first thing is that we want to look at very seriously
16 the results of the study and--and integrate some of
17 those unmet needs into that \$4 million pot, which
18 will add to the \$4 million that we have from the
19 federal government. So, we're looking to double the
20 amount of respite that we provide, homecare and give
21 families the greatest flexibility in what they need
22 for their loved one because it's different for
23 people, right, depending on where they live, what
24 their needs are, what their circumstances are. So,
25 we're trying to develop a way that we give them the

2 greatest flexibility with support service. For
3 example, if you need respite, respite to one person
4 may be different than respite from another person.
5 So, they can go out and purchase it in the open
6 market. They can purchase it, whatever it is that
7 they need. For example, if-if it's a grandparent
8 raising grandchild for-for example, and they need
9 maybe to go to camp for week, that would provide
10 respite and it's a very needed service, we may be
11 able to provide that, and give our contracted
12 providers the flexibility to do that. So, we have to
13 come up with a mechanism that we can expand the
14 program that-that we can hold our community providers
15 accountable, but also give them the greatest
16 flexibility.

17 CHAIRPERSON CHIN: So--

18 COMMISSIONER DONNA CORRADO:

19 [interposing] So, there might be homecare for some
20 person. It might be transportation that they would
21 purchase. It might be a social adult day program.
22 It might be overnight respite. So, we're trying to
23 give them the greatest amount of flexibility and-and
24 have individualized care plan and client centered
25 care. So, that's--so, we're not going to just throw

2 it all out and say we're going to, you know, put it
3 all--all of our eggs in one basket because we need--we
4 realize that people's needs are different and they're
5 different at different times.

6 CHAIRPERSON CHIN: So we have information
7 about how much respite care is being provided now
8 from the DFTA contractors?

9 COMMISSIONER DONNA CORRADO: Oh, yes, we
10 do. So, we have those levels, and we hope to double
11 if not triple that with the investment that's being--
12 currently being made, and then we'll grow that in the
13 future, but we have to build capacity. There's no
14 doubt about it. We have ten caregiver programs now.
15 They go up for RFP so there may be a different set of
16 players in 2020, and we will grow capacity as we go
17 along, and we want to do it in a thoughtful and a
18 planful way, but be responsive to what individuals
19 need and what families need, and we agree with you--

20 CHAIRPERSON CHIN: [interposing] Well, I
21 think that's good for us, too. I mean we would like
22 to know in terms of--

23 COMMISSIONER DONNA CORRADO: Uh-hm.

24 CHAIRPERSON CHIN: --what's being offered
25 now--

2 COMMISSIONER DONNA CORRADO: Uh-hm.

3 CHAIRPERSON CHIN: --so that we can see
4 what do you mean by doubling it? You know, how many
5 people are--

6 COMMISSIONER DONNA CORRADO: Sure.

7 CHAIRPERSON CHIN: --receiving respite
8 care now, and with the additional budget? I mean one
9 of the things that I'm concerned about right now we
10 are in the end of November. Almost half the Fiscal
11 Year is gone. So, I want to make sure that that \$4
12 million that was baselined get out there to the
13 contractors. So, are you in the process of amending
14 providers' contracts

15 COMMISSIONER DONNA CORRADO: [interposing]
16 So, that--that's--

17 CHAIRPERSON CHIN: --so that they can get
18 the money?

19 COMMISSIONER DONNA CORRADO: --that's the
20 most expeditious way for us to do that is to amend
21 contracts, the existing providers contracts, which we
22 will be doing. So, will get done in short order,
23 probably by the beginning of the year. So, we hope
24 to see that, and then from there we will RFP in the
25 future so that other providers can come in, and we

2 can grow the program accordingly. But actually,
3 Robin has the numbers with the current respite and
4 what our projections are with additional monies.

5 ASSISTANT COMMISSIONER FINLEY: So,
6 you're see in the testimony that Dr. Corrado gave,
7 you know, the doubling. So, if we look at Fiscal
8 Year 17 for the individual homecare, there have been
9 340 individuals served unduplicated individuals, and
10 we're looking for those to grow to 676 by the end of
11 Fiscal Year 19. Looking at Fiscal Year 19 as the
12 first fully year of utilizing these dollars. Group
13 Respite is currently 193 looking to move that up to
14 390, and the overnight and other respite is 92
15 individuals served. Looking to move that to 272, and
16 supplemental services 616 caregivers and looking to
17 move that to 775. One of the things that we intend
18 to do with this funding is from the benefit of this
19 survey knowing the areas and certainly the areas of
20 need, we intend to do an information campaign. You
21 could hear the campaign or you could hear the
22 information as most requested service, and so through
23 the results of the survey, we feel that we're going
24 to be able to target areas of the city to give the
25 information so that when Council Member Vallone has

2 people coming into his office, they will have heard
3 about caregivers. We also have from our ten
4 caregiver programs, they all do outreach as well, and
5 I know that they translate their materials for the
6 populations that they serve. And so this is--as the
7 Commissioner was saying, this is a beginning effort,
8 and to make a planful approach to respond to the
9 needs of this absolutely growing population.

10 CHAIRPERSON CHIN: Okay, one last
11 question. What-what is the--can you explain a little
12 bit more about what is the supportive and
13 supplemental services--

14 ASSISTANT COMMISSIONER FINLEY:
15 [interposing] Sure.

16 CHAIRPERSON CHIN: --that's been provide?

17 ASSISTANT COMMISSIONER FINLEY: Sure, in
18 some instances thinking about the visually impaired
19 caregiver who themselves might be visually impaired
20 caring for someone who is also visually impaired.
21 Medicaid where we can have our caregiver providers
22 utilize Medicaid and other funding sources, they're
23 always encouraged to go that way. However, we've
24 discovered that Medicaid doesn't pay for such
25 fundamental things as the canes, and--and other sort

2 of assistive devices that if you want—as the
3 caregiver you're care receiver is—wants to go outside
4 and go, you know, do the normal activities, and if
5 without having those supportive devices you are not
6 at all relaxed. And so when you're thinking about
7 respite as giving a break to the emotional strain of
8 the caregiver, something as simple as a cane is
9 helpful in that end, and so supplemental services can
10 be a wide, wide range. We can have individuals who
11 don't have the funds to purchase the incontinence
12 garments, Ensure and things of that sort. So, it's—
13 and again, it all depends, as you're hearing today in
14 the testimony, every situation is different, and so
15 the care needs will be different both for the
16 supplemental services, and truthfully I'm hoping that
17 out of our and for—and technology, the right use of
18 technology we are—I'm—I'm hopeful that we're going
19 to find from some communities that we are not fully
20 engaging some kind of respite that we don't even know
21 about yet. What's going to work for this family?
22 What's going to work for this individual? So, it's a
23 flexibility and a creativity that's going to come
24 organically from the caregiver through the programs
25 that we're hopeful to be able to help with.

2 CHAIRPERSON CHIN: Council Member

3 Deutsch.

4 COUNCIL MEMBER DEUTSCH: Thank you. So,
5 my first question is you mentioned in your testimony
6 that the cost of unpaid caregivers in the United
7 States is an estimated cost of \$470 billion per year.
8 What would the cost estimate for the 1.3 million
9 caregivers in New York City?

10 ASSISTANT COMMISSIONER FINLEY: Yeah. I
11 think we have to work on that.

12 COMMISSIONER DONNA CORRADO: So, that I
13 mean, that the economic value if they were to be paid
14 in New York City is upwards of \$25 billion if we were
15 to pay them for the work that they do when they
16 leverage. Now, that's not practical, right? It's
17 \$25 billion we don't have sitting around somewhere
18 but we need to support them so that they can continue
19 to leverage \$25 and someday \$50 billion worth of-of-
20 of goods and services that are unpaid and going into
21 the system. Because there's, you know, we—we
22 recognize that—that in many ways society is getting,
23 you know, help for free by unpaid informal
24 caregivers, and we want to grow the informal network.
25 We don't want it to shrink in anyway. We're not

2 saying that we have to turn around and necessarily
3 pay everybody that provides care for their loved one,
4 but we do need to make life easier for them, and
5 that's really the gist of what we're saying and what
6 we're doing, and it is—it's a—it's a woman's issue as
7 well, right? It's—it's—there's a—the number of
8 female caregivers traditionally, you know, throughout
9 the ages, but this is a—a woman's issue, and it's a
10 family issue, and we need to support them so that
11 they can continue to provide informal unpaid
12 caregiving. And—and that's just alongside of the
13 paid caregiver network that is—has in and of itself
14 its own host of issues in terms of how do we support
15 the paid long-term care workforce. So, that's a
16 whole other discussion, whole topic, but we're
17 simultaneously working in both of those worlds so we
18 can support them because we all need—know that we
19 need a lot more care to give as people grow older and
20 their needs are greater.

21 COUNCIL MEMBER DEUTSCH: Thank you. So,
22 obviously it will be very costly if—if the 1.3
23 million caregivers are paid, and we do have an
24 obligation. We have a responsibility as a city to
25 take care of each—each and every caregiver.

2 COMMISSIONER DONNA CORRADO: Uh-hm.

3 COUNCIL MEMBER DEUTSCH: So, in the
4 budget in Fiscal Year 17 you did mention that \$4
5 million is a base—is that \$8 million was allocated in
6 Fiscal Year 17 and for \$4 of the million were
7 baselined, which served 6,200 individuals and we have
8 1.3 million caregivers, and I just wanted to
9 reiterate what Chair Vallone mentioned that 6,200 our
10 of 1.3 is really like drop in the bucket, but you did
11 mention that we are looking—that Department of Aging
12 is looking to go out there and reaching out to all
13 those caregivers and really to—what we need to do is
14 reach out to the 1.3 million people, but what wasn't
15 mentioned is that although hey are unpaid caregivers,
16 and we have \$8 million in Fiscal Year 17 Budget, what
17 would the cost be to help those 1.3 million unpaid
18 caregivers? What would this—what would that cost be
19 for New York City?

20 COMMISSIONER DONNA CORRADO: That's very
21 difficult to determine just because of the varying—
22 the various needs of individual caregivers. We don't
23 know what they are because we don't, you know, we're
24 not necessarily assessing every single one of them,
25 and my—and we—we also know that although the

2 Department for the Aging may not be caring fro them,
3 there are other systems and supports that may be
4 caring for them. For example, the Medicare system or
5 the disabilities world. There's a--there's a
6 tremendous amount of services and supports available
7 to people that are disabled, and for caregivers of--of
8 people that have disabilities, and there's the whole
9 foster care world and all of that. So, we--we have to
10 also be mindful that the Department for the Aging is
11 just one piece of the puzzle, but certainly there is
12 support available for people, and there is a
13 tremendous gap in services and needs for older people
14 and older caregivers as well.

15 COUNCIL MEMBER DEUTSCH: Thank you and,
16 you know, the point is that we come to a hearing and
17 we hear testimony yeah, we have to do more. We have
18 to reach out to the 1.3 million, but if we in the
19 City Council, and when it comes to budget hearings,
20 if we don't have a cost estimate for how much we need
21 to advocate for the Department for the Aging to reach
22 out to the 1.3, and not only reaching out to the 1.3
23 but caring for the 1.3 million people. So, if--if
24 it's a difficult question to answer because we don't
25 have that cost estimate of what it would cost to have

2 1.3 million unpaid caregivers, then why are we—why
3 are we sitting here? We have nothing to talk about
4 really, and also the Department for the Aging has
5 also a—I'm sure you have a budget on advertising
6 costs of how much you—you advertise.

7 COMMISSIONER DONNA CORRADO: Right.

8 COUNCIL MEMBER DEUTSCH: So, you know,
9 I've seen those pass in the City Council and I've
10 seen billboards about things that really don't make
11 sense because we don't put out billboards on every
12 bill that is passed to let people know, but this is
13 important. So, I have not seen any billboards out,
14 any—and signage out or any posted in bus shelters,
15 in—in other areas. I have not seen anything, but
16 what—what I have seen is that some nonsense things,
17 which really confuse people where the city is paying
18 for advertisement, which I don't really get because
19 sometimes I don't understand what the billboard says.
20 There's too many words in there that nobody has time.
21 You know at bus shelters yes people have time because
22 the buses run late anyway, but in other areas, really
23 people, it just confuses them. So, I think that there
24 should be some type of adver—you know, um—um,
25 outreach on billboards just plan and simple: Are you

2 a caregiver? Please call. We are here to help. You
3 know, it's really simple and basic--

4 COMMISSIONER DONNA CORRADO: We agree
5 with you.

6 COUNCIL MEMBER DEUTSCH: --and I don't
7 see it. I don't see it anywhere. So, so again,

8 COMMISSIONER DONNA CORRADO:

9 [interposing] But, you know--

10 COUNCIL MEMBER DEUTSCH: --I just want
11 to--I just want to go back and say that we need to
12 know how much it--how much the cost is before the next
13 budget--

14 COMMISSIONER DONNA CORRADO: Uh-hm.

15 COUNCIL MEMBER DEUTSCH: --to-to the
16 Department for the Aging to provide for the--for the
17 community-based organizations for them to provide
18 care and help and resources and support to 1.3
19 million people who are unpaid caregivers.

20 ASSISTANT COMMISSIONER FINLEY: May I
21 just jump in. Your point is well taken. I just want
22 to acknowledge that not all caregivers are--are
23 providing the kind of care to the extent--we're
24 talking about a wide array of service provisions, and
25 assistance that families. So that we've had many

2 instances where we would offer services to a
3 caregiver who will say I'm fine. Give it to someone
4 else. So-so, to support Commissioner Corrado, it is
5 a challenge to find out who are--of those 1.3, who
6 are those individuals who really need an will accept
7 and benefit from the services or the funding that
8 we're talking about today.

9 COUNCIL MEMBER DEUTSCH: Agreed, but if
10 you have 6,200 people--individuals that were--that were
11 helped, 1.3 so let's not call it 1.3 million. Let's
12 call it 20,000 or 30,000 or 40,000 people. We have
13 no cost.

14 ASSISTANT COMMISSIONER FINLEY: Fair.

15 CHAIRPERSON CHIN: Council Member
16 Koslowitz, do you have a question?

17 COUNCIL MEMBER KOSLOWITZ: Thank you.
18 You know, I'm sitting here and I'm listening to this
19 and I have to tell you it's the first time I've heard
20 about this (coughs) and it's shame because we have
21 people calling our office all the time, and they
22 haven't heard about it. We needed the survey of the
23 18,000 people and you only got 2,000 responses. Is
24 that correct?

25 JOSHUA SIDIS: Yeah.

2 COUNCIL MEMBER KOSLOWITZ: Is that what I
3 heard?

4 JOSHUA SIDIS: Yes, that's correct.

5 COMMISSIONER DONNA CORRADO: Yes.

6 COUNCIL MEMBER KOSLOWITZ: (coughs) Where
7 were those 2,000 responses from? What part of the
8 city?

9 COMMISSIONER DONNA CORRADO: So, I gave a
10 lot of thought to this and working with the
11 researchers at the Department for the Aging, and
12 Westat, we sort of challenged that: Why only 2,000
13 responses when you're targeting caregivers, but then
14 when you think about it, what do caregivers not have?
15 Time to answer a survey. So, in a sense that—that
16 makes sense to me, because you're—you're asking a
17 caregiver to stop what they're doing in their busy
18 day and answer a survey that was quite extensive and
19 comprehensive. So, I'm not—when I thought about it,
20 well, I'm not really so surprised if we—if we
21 targeted 18,000 known caregivers and only 2,000
22 responded, I think that's a pretty good response
23 rate, and it's actually better response than most
24 surveys get, and that would with—it's a statistically
25 significant response to a survey, right? So, if

2 you're caring for a loved one, and you—and you—you're
3 holding down a full-time job and you're running here
4 and you're running there, the last thing you want to
5 do is answer a survey from a strange that calls up—
6 calls you up on the phone. So, that—that's kind of
7 understandable, but the important thing is we got
8 2,000 people responded to the survey in a way that
9 those survey's responses were valid responses. I
10 mean and it's really validating what we already knew
11 what they needed, and there's—and in addition to our
12 survey, part of the—of the research was looking at
13 what's been done because there's a whole body of
14 caregiver research that's been done in the last two
15 decades. So, we can look at that as well, and—and—
16 and come up with some recommendations looking not
17 only at our survey results, but looking at what's
18 been done in the past.

19 COUNCIL MEMBER KOSLOWITZ: But we can
20 reach so many more people.

21 COMMISSIONER DONNA CORRADO: But we
22 could—but we're talking about a survey now.
23 [coughing] We're not talking about a program.

24 COUNCIL MEMBER KOSLOWITZ: [interposing]
25 I understand that, but what I'm saying to you is if--

2 COMMISSIONER DONNA CORRADO: [interposing]

3 We can't--

4 COUNCIL MEMBER KOSLOWITZ:--you give the
5 information. For instance, I have a 20,000
6 constituent--

7 COMMISSIONER DONNA CORRADO: Right.

8 COUNCIL MEMBER KOSLOWITZ: --email.

9 COMMISSIONER DONNA CORRADO: Uh-hm.

10 COUNCIL MEMBER KOSLOWITZ: If you give us
11 the information, we can get it out there also.

12 COMMISSIONER DONNA CORRADO:
13 [interposing] Okay, so, we've got this--

14 COUNCIL MEMBER KOSLOWITZ: [interposing]
15 That's how we represent because--

16 COMMISSIONER DONNA CORRADO: [interposing]
17 But that's one, but that's one way.

18 COUNCIL MEMBER KOSLOWITZ: The truth of
19 the matter is my community is the last to hear about
20 anything.

21 COMMISSIONER DONNA CORRADO: Well, we
22 don't know that because we don't know who was sampled
23 in your community, and--and in all due respect, this
24 was a professional research organization that does
25 this. You know, that is their reason for being. So,

2 whether your constituents were sampled or not, I
3 don't know, but maybe many of them were, and we—we
4 did it in a way so that it's not necessarily a biased
5 sampled, and there's all things that—that are very
6 important when you do to have a valid survey that
7 you—that you look at. But we know because we've—and
8 then we've crossed that survey sample with another
9 survey sample that AARP did, and they validated each
10 other's results. So, if you look at the two sides,
11 there was the one survey sample and then the AARP
12 survey sample. The results were pretty consistent
13 across the board.

14 COUNCIL MEMBER KOSLOWITZ: But what I'm
15 saying is that out of 18,000 there were many more out
16 there, more than 18,000.

17 COMMISSIONER DONNA CORRADO: Absolutely.

18 COUNCIL MEMBER KOSLOWITZ: So, if you
19 sent it let's say to my office--

20 COMMISSIONER DONNA CORRADO: Uh-hm.

21 COUNCIL MEMBER KOSLOWITZ: --I could help
22 you out.

23 COMMISSIONER DONNA CORRADO: I thank you
24 and next time we will—we may have even given them the
25 Council Members' number if they needed to increase a

2 sample. So, I'm not exactly sure how they got and
3 what they use.

4 JOSHUA SIDIS: [interposing] So we--sorry,
5 Commissioner.

6 COMMISSIONER DONNA CORRADO: That's
7 alright.

8 JOSHUA SIDIS: So, for this time around
9 we reached out to known caregivers or rolls that had
10 caregivers on it, if that's--if I'm not mistaken, and
11 I also want to note to a couple of points that were
12 made earlier, part of this process was doing a
13 demographic analysis before we sent out the survey to
14 make sure that it was reflective of--of the city, and--
15 and we did that, and then we did a randomized sample
16 based on that. And not significantly smaller than
17 the--than the surveys that we sent out, than the--than
18 the samples that we were reaching out to, but it--it--
19 it--and then I also want to say the next thing, which
20 is Local Law 97 allows us to come back in two years
21 and do another survey, right, and so that is another
22 bite at the apple for us to do a greater number of
23 outreach. You know, I think what we've done here is
24 set a baseline, as the Commissioner has--has noted of
25 empirical evidence. It's--it's--we hear you loud and

2 clear. These are all things that you know. Now, we-
3 we have, you know, we have-we have it on paper. We
4 have it in-in data tables. We have it ready to look
5 at, and then we can build on that in two years, and
6 recognizing that we do-we will need to do-we, you
7 know, we'll find other means in-in two years to-to
8 reach out to more constituents. But I think for this
9 time around, I-I-it's important to note that we-we
10 reached out to known caregivers.

11 CHAIRPERSON CHIN: Okay, also the-the law
12 also requires that you have a breakdown in terms of
13 results by district, by Council District. So, I
14 think that's something that you need do share with
15 us-

16 JOSHUA SIDIS: Yes.

17 CHAIRPERSON CHIN: --so that we can see,
18 you know, how many people were sampled in a district
19 or how many people responded from each district.

20 JOSHUA SIDIS: Uh-hm.

21 CHAIRPERSON CHIN: This certainly would
22 give us a better view of what's-what the picture is
23 and, of course, two years later you got to d another
24 one.

25 JOSHUA SIDIS: Yes.

2 CHAIRPERSON CHIN: It's mandated.

3 JOSHUA SIDIS: It's mandated. It is.

4 CHAIRPERSON CHIN: Council Member.

5 COUNCIL MEMBER KOSLOWITZ: I-I just want
6 to finish up by saying I get tons of sur-surveys in
7 my mail almost everyday about different things that
8 are happening, and truthfully, most of them I don't
9 even look at. I just throw it in the garbage
10 because, you know, I don't have the time to sit down
11 and answer all these surveys. So, again I say if you
12 let us know about what is going on, we could help
13 you. I mean there are 51 Council Members that would
14 be more than happy to help you. You know, to help
15 these caregivers. I mean I-I have a very personal
16 feeling about this because I was a caregiver to my
17 mother many years ago, and it's a very hard thing to
18 do. I had to go to work. It is my-I was all over
19 the place. I was nervous and upset. So, I know how
20 important it is for people to know about taking care
21 of-of their parents or-r someone else. So, I have a
22 very strong feelings on this. Thank you.

23 CHAIRPERSON CHIN: Thank you. Council
24 Member Vallone.

2 COUNCIL MEMBER VALLONE: Thank you,
3 Chair. Just a couple of quick follow-ups. Within
4 our own case management files, is there a category
5 acknowledging whether there's a caregiver in the
6 family or present or needed?

7 COMMISSIONER DONNA CORRADO: [on mic]
8 Absolutely. [on mic] Absolutely.

9 COUNCIL MEMBER VALLONE: So would that--

10 COMMISSIONER DONNA CORRADO: [interposing]
11 It's part of the assessment that the informal
12 caregivers and whatever informal supports are
13 available is in the--not only in the assessment, but
14 also part of the care plan. So, that's a given.

15 COUNCIL MEMBER VALLONE: So, I don't--
16 that's not part of the 2,000. That would be our own--
17 -

18 COMMISSIONER DONNA CORRADO: [interposing]
19 So, no, that--and that's another point, right? It's
20 not part of the 2,000. We're talking about a survey
21 sample. That's all we're talking about. We're not
22 talking about the universe of caregivers. We're not
23 talking about anything else other than 2,000 people
24 responded to a survey sample of 18,000.

25 COUNCIL MEMBER VALLONE: That's hard.

2 COMMISSIONER DONNA CORRADO: That's all
3 we're talking about.

4 COUNCIL MEMBER VALLONE: Surveys are very
5 hard to--

6 COMMISSIONER DONNA CORRADO: [interposing]
7 And--and what's available to caregivers--let's not, you
8 know, there's--the Department for the Aging has a \$366
9 million budget. So, everything that we do or the way
10 I see it is really supporting a caregiver whether
11 it's a senior center, whether it's a case management
12 program, home delivered meals those are all services
13 and supports for caregivers. So, it's not to say
14 that we didn't hear about anything that--that the
15 department does as it relates to caregivers. This
16 all part of the long-term care service and support
17 network including the tremendous amount of outreach
18 that's been done in the past year to talk about the
19 Aging and Disability Resource Center and New York
20 Connects and 311 and all of that that's available,
21 and there's a tremendous campaign throughout the
22 state and through the Department for the Aging as
23 well.

24 COUNCIL MEMBER VALLONE: No, I agree with
25 you. It's just--

2 COMMISSIONER DONNA CORRADO: [interposing]
3 So, it's all part of the same thing. We want to help
4 people help older people.

5 COUNCIL MEMBER VALLONE: But I'm just
6 looking for the--that--that number. I don't know if
7 you have it today, but since we have that database,
8 that would give us a rather accurate number of the
9 actual caregivers. Not the ones that actually
10 responded to the survey because like you said,
11 though--

12 COMMISSIONER DONNA CORRADO: [interposing]
13 Right.

14 COUNCIL MEMBER VALLONE: --it's very hard
15 get anyone through me. I just don't--as soon as a
16 survey comes up in my email, it's like this. I want
17 my life to go on so I'm not going to do it, so--

18 COMMISSIONER DONNA CORRADO: Right. So,
19 that would be a sample of a sample. So, we would
20 still be extrapolating.

21 COUNCIL MEMBER VALLONE: And do we have--
22 do we have the number of caregivers--?

23 COMMISSIONER DONNA CORRADO: [interposing]
24 So, we--we do have that number and we've--we've
25 extrapolated in many different ways looking at

2 different samples, and there's different ways to come
3 around a number. The important piece is the number
4 is tremendous. It's a great number of people. So,
5 we can say 1.3 million, 1.5 million, 2 million. At
6 what point does it become, you know, a ridiculous
7 number? We know that we have many more people to
8 help and support.

9 COUNCIL MEMBER VALLONE: So, that's how we
10 got 1.3?

11 COMMISSIONER DONNA CORRADO: We got to
12 1.3 by looking at different data samples through a
13 national survey and looking at New York State data,
14 and looking at New York City and extrapolating that.
15 That was not a hard number. So, we're saying that
16 there's approximately 1.3 million. It could be 900,
17 it could be 5 million. We don't know, but our best
18 guesstimate is that it's upwards of 1.3 million.

19 COUNCIL MEMBER VALLONE: I'm just
20 thinking out of the box. I mean that might be a
21 number that we can all help to determine because like
22 I said with the bar associations and groups that are
23 doing this with our nursing homes, our assisted
24 living, our senior centers, that could be a real
25 quick check of the box of is there a caregiver in the

2 family? Are you a caregiver? Are you dependent on a
3 caregiver? And then we'd be able to get that
4 information rather quickly to you.

5 JOSHUA SIDIS: Uh-hm.

6 COUNCIL MEMBER VALLONE: One good thing
7 that you said, which I think would help the Chair and
8 I going forward was the quickest way to deal with
9 this was to amend existing contracts--

10 COMMISSIONER DONNA CORRADO: [interposing]
11 We have—we-

12 COUNCIL MEMBER VALLONE: --and issue new
13 RFPs. Could you just explain that?

14 COMMISSIONER DONNA CORRADO: Okay. So,
15 currently we have ten caregiver contracts out with
16 various community-based organizations that we fund to
17 provide caregiver services. That's the original
18 investment through the National Family Caregiver Act
19 the federal government pays for. So, we're building
20 on that program by funding those community-based
21 providers that we have a known—they're know entities
22 to us. They currently have programming. They're
23 familiar with the work. We'll amend those contracts
24 to include the \$4 million. That's the best way to
25 get programs up and running in a quick way.

2 COUNCIL MEMBER VALLONE: So when does that
3 happen?

4 COMMISSIONER DONNA CORRADO That's going
5 to be now.

6 COUNCIL MEMBER VALLONE: Okay.

7 COMMISSIONER DONNA CORRADO: So, we're
8 currently going to be—we're amending contracts right
9 now, and figuring out, you know, the—the finances of
10 it working with the OMB, and then in the future we'll
11 be RFPing. As—as part of the natural RFP cycle,
12 those contracts come up for renewal. So, we'll be
13 RFPing for it. It may be an opportunity for us to
14 expand the number of caregiver contracts, contract
15 the number of contracts that we currently have and
16 expand the program. So, it may not be necessarily
17 the same providers going forward in the future.

18 COUNCIL MEMBER VALLONE: I think those are
19 the important steps--

20 COMMISSIONER DONNA CORRADO: [interposing]
21 Uh-hm.

22 COUNCIL MEMBER VALLONE: --that we can
23 focus on going forward that we can immediately help
24 with and get the services out rather quickly--

25 COMMISSIONER DONNA CORRADO: Right.

1 COMMITTEE ON AGING

68

2 COUNCIL MEMBER VALLONE: --without a
3 survey or not.

4 COMMISSIONER DONNA CORRADO: Right,
5 right.

6 COUNCIL MEMBER VALLONE: Those are your
7 ten groups.

8 COMMISSIONER DONNA CORRADO: Right.

9 COUNCIL MEMBER VALLONE: And I think I'd
10 be excited to then work on that.

11 COMMISSIONER DONNA CORRADO: Thank you.

12 COUNCIL MEMBER VALLONE: Thank you,
13 Chair.

14 CHAIRPERSON CHIN: Thank you. A couple
15 of follow-up questions. In the Mayor's Management
16 Report they indicated a fluctuation of the number of
17 caregivers who access this service like for FY16 it
18 was 11,342 and then it went down to 10,201 in FY17.

19 ASSISTANT COMMISSIONER FINLEY: Uh-hm.
20 Right, those are--those reflect the numbers for the
21 Caregiver Resource Center within the Department for
22 the Aging, and--and I think in part we also were
23 funneling some of the calls to our New York Connects
24 providers so they did not stay in--in house but, you
25 know, would still get the same services. But there's

2 also sort of an inexplicable high and low of
3 caregivers requesting services. You know, it seems
4 as though sometimes in the holiday season after
5 holiday seasons the numbers increase, and in
6 summertime they lower or, you know, vice versa.
7 It's—it's a little bit hard to explain, but when you
8 look over time there is that trend of raising and
9 lowering.

10 CHAIRPERSON CHIN: In either the Local
11 Law 1 of 2016 added family caregivers to the New York
12 City Human Rights Law. So, does the Human Rights
13 Commission provide training to DFTA staff and the
14 contract providers regarding Local Law 1?

15 COMMISSIONER DONNA CORRADO: Not that I
16 know of.

17 ASSISTANT COMMISSIONER FINLEY: Yeah, to
18 date not that we're—not that we've been approached
19 on.

20 CHAIRPERSON CHIN: So, they haven't done
21 that:

22 ASSISTANT COMMISSIONER FINLEY: It's an
23 age-friendly initiative, and as a partner in the age-
24 friendly initiative, certainly conversation can go
25

2 for that, and I think it would be a value for the
3 programs and for us.

4 CHAIRPERSON CHIN: Well, I mean a person
5 can call 311 and then refer to the Human Right
6 Commission for issues regarding caregiver
7 discrimination. So, it's important I guess to make
8 sure that in terms of inter-agencies and stuff that
9 DFTA staff and also the provider knows that. So, if
10 that's an additional service resources that a
11 caregiver--

12 ASSISTANT COMMISSIONER FINLEY:
13 Certainly.

14 CHAIRPERSON CHIN: --can access--

15 ASSISTANT COMMISSIONER FINLEY: Right.

16 CHAIRPERSON CHIN: --we got to be sure
17 that--

18 ASSISTANT COMMISSIONER FINLEY: Right,
19 we've got to develop points of contact. That's an
20 excellent point.

21 COMMISSIONER DONNA CORRADO: Yes, that's a
22 good idea.

23 ASSISTANT COMMISSIONER FINLEY: Uh-hm.

24 CHAIRPERSON CHIN: So, that's something
25 that you should reach--reach out to the Human Rights

2 COMMISSIONER DONNA CORRADO: Okay.

3 CHAIRPERSON CHIN: --Commission and for
4 some of the trainings.

5 COMMISSIONER DONNA CORRADO: Okay we
6 will.

7 CHAIRPERSON CHIN: So, I think the--the
8 last point is like a--with the funding even if you
9 amend the contract, you might not be using up all the
10 funding this year. So, are you--because in your
11 testimony earlier you were saying that you really do
12 some more extensive outreach. So, are you going to
13 take some of that money to really publicize resources
14 that are available? So, are we going to see some--I
15 don't know about billboards, but at least subway
16 signs or--

17 COMMISSIONER DONNA CORRADO: Yes.

18 CHAIRPERSON CHIN: --bus shelter signs
19 telling people that the numbers they can call or
20 services that might be available if you are a
21 caregiver?

22 COMMISSIONER DONNA CORRADO: Right. So,
23 the public outreach piece will be a part of the plan.
24 Yes. So, we will spend some of that money doing an
25 extensive public outreach campaign to help people

2 identify as caregivers and to direct them to the
3 resources that are available. Yes.

4 CHAIRPERSON CHIN: At least we know the
5 money is there.

6 ASSISTANT COMMISSIONER FINLEY: Yes.

7 CHAIRPERSON CHIN: Yes, and we just want
8 to make sure that that--

9 ASSISTANT COMMISSIONER FINLEY:
10 [interposing] That's money well spent.

11 CHAIRPERSON CHIN: --money will get out
12 the door and spent.

13 COMMISSIONER DONNA CORRADO: Yes.

14 CHAIRPERSON CHIN: And I'm sure the
15 provider is anxiously waiting because they--

16 ASSISTANT COMMISSIONER FINLEY:
17 [interposing] They are.

18 CHAIRPERSON CHIN: --definitely can
19 increase the--the services they provide.

20 ASSISTANT COMMISSIONER FINLEY: Yeah,
21 they're very excited about it. We all are.

22 CHAIRPERSON CHIN: Do you have any other
23 questions? Council Member Rose, do you have any
24 questions?

25 COUNCIL MEMBER ROSE: No.

2 CHAIRPERSON CHIN: Uh-hm. Okay. Well,
3 thank you for coming in today to testify, and we look
4 forward to continuing working with you--

5 COMMISSIONER DONNA CORRADO: Yeah, than
6 you.

7 CHAIRPERSON CHIN: --and providing
8 services for out caregivers.

9 COMMISSIONER DONNA CORRADO: Thank you.

10 CHAIRPERSON CHIN: We're going to call
11 the next panel. [pause] Caitlin Hosey from Live On
12 New York. [background comments] Chris Widelo from
13 AARP. Jane Fialko from SAGE and Jeff Levine from
14 Caring Time. [background comments, pause] You may
15 begin.

16 CAITLIN HOSEY: Well, hello. I'm Caitlin
17 Hosey. I'm here representing Live On New York.
18 First, I want to thank Council Member Chin, the Chair
19 of the Aging Committee and the entire committee for
20 having this important hearing today. Of course, I
21 also want to thank the Mayor, Speaker, Finance Chair
22 Julissa Ferreras-Copeland and the Aging Chair, and
23 DFTA Commissioner Donna Corrado for last year's
24 really big win for the Year of the Senior, which
25 added the \$4 million in caregiving funding as well as

2 a real total increase for the infrastructure of aging
3 supports in New York City. We are really
4 appreciative and excited about that. So, first, I'm
5 really excited to comment on the survey of informal
6 caregivers in New York City, it's exciting to see
7 attention being paid—being paid to this important
8 issue. The findings that one-half of all caregivers
9 provide at least 30 hours or more of caregiving each
10 week is astounding, and the fact that this is often
11 mostly women, it's—it's important for us to know, and
12 to take stock of when we're thinking about caregiving
13 supports moving forward. Three-fourths of all of the
14 caregivers surveyed were over the age of 55. So,
15 often these are seniors themselves maybe caring for a
16 younger loved one or a senior relative, whatever that
17 may be. So, this issue skews to be an aging issue.
18 The need for information and referral was found to be
19 really important. People don't know about the
20 services that exist, which is why we're really
21 excited about the New York Connect Program that has
22 gotten up and running, and we really are appreciative
23 of the providers in each borough that run this
24 program. We advocate for continued support for the
25 New York Connect Program and for the restoration of

2 funding that was previously lost in the State's
3 Budget so, of course, that's a State issue, but we
4 just wanted to put that on your radar. We want to
5 bring city attention, which has already been shed
6 light on today, the importance of—the important role
7 that caregivers bring to the overall economy of New
8 York so caregivers give back. New York State as a
9 whole benefits about \$32 billion annually. From one
10 study that we've read, 28% of grandparents are
11 raising grandchildren. So, that not only helps to
12 develop our youth, but alleviates strain on the
13 Foster Care system. So, seniors, caregivers they're
14 giving back and it impacts a variety of sectors, and
15 we just really want to make sure that given that
16 support that caregivers are giving themselves that we
17 are supporting them financially, emotionally through
18 all of their needs. Of course, we've mentioned that
19 caregiving is often a woman's issue, but it really
20 does make up every race, gender, socio-economic
21 status. There is nobody that is off limits in
22 becoming a caregiver or having to take on that role
23 for a loved one. We also want to mention the unseen
24 workforce that's funded by DFTA. All of the DFTA
25 services are caregiving services in reality. Social

2 Adult Day when you or a loved one able to know that
3 your senior relative is able to spend the day in a
4 safe social-social adult day program. That's a huge
5 relief. You can go to work for eight hours and not
6 have to worry. The same being said for a senior
7 center or even home delivered meals not having to
8 thank about cooking a hot meal everyday for your
9 loved one. May you're too far away. Maybe you don't
10 live in the city, and you're unable to provide for
11 that. So, this network of services really is so
12 complementary to the caregiving program itself. But
13 we just wanted to make sure that that is also seen as
14 the full picture of caregiving services. These
15 programs are cost-effective. The amount of money
16 that goes into a senior center budget all of that it
17 comes back tenfold. These services really support
18 the network of senior-senior caregivers, and they-the
19 return on investment is just huge. We are going to
20 continue to advocate for strengthening the entire
21 system. The Caregiving program that was started this
22 year as well as the entire system of DFTA funded
23 services in FY19 we want to continue the momentum
24 that started in the Year of the Senior this upcoming
25 year. So, we call for continued investment to be

2 made and—and funding increases as the years move on,
3 and as the number of caregiver—caregivers continue to
4 increase. So, we really thank you for your support,
5 and your interest in tackling this important issue,
6 and we look forward to working with you in the
7 upcoming budget season.

8 CHRIS WIDELO: Good morning, Chairwoman
9 Chin, Council Member Vallone and Rose and thank you
10 for the opportunity to talk today. My name is Chris
11 Widelo. I'm with AARP, and you probably know that
12 caregiving is one of our top priorities as a—as a
13 nationwide organization and, of course, here in New
14 York State and in the city, and again thank you for
15 all that you have done to ensure that-- You know,
16 we've had increased funding in the—in the city
17 budget. It's—it's needed and, you know, thanks to
18 your advocacy and fighting here in the Council, you
19 know, we can really look back on a great year for
20 aging services here in the city. But we know that
21 more needs to be done. So, you know, Caitlin
22 mentioned about that the value of this unpaid care is
23 about \$32 billion nationwide—statewide. It comes
24 down to almost about \$13 billion here in New York
25 City. That's a considerable savings that the city is

2 not having to pick up a few more costly forms of
3 caregiving. And while many family caregivers
4 wouldn't have it any other way, it's a big job and
5 you never truly understand what a caregiver goes
6 through until you find yourself in that position, and
7 that's a position I'm finding myself in now, and
8 despite being-working in this field, I still find
9 myself confused as to where to go and what to do, and
10 how-how to access and making the right decisions.
11 We've had-you know, AARP has had the opportunity to
12 hear directly from a lot of the formal family
13 caregivers through some listening sessions that we've
14 held, and one of the themes that always comes up is
15 the red tape of the process. You know, or that they
16 don't have access to the resources that they need to
17 successfully do their job and it's heartbreaking, and
18 I think what's even more concerning is that many of
19 these caregivers are unable to care for themselves
20 and take the time to recharge so they can provide
21 that continued service to a loved one. If you're
22 ever interested in some real stories from people to
23 hear what they are going through, AARP has a website
24 I Heart, heartcaregivers.com. and people are able to
25 post their caregiving stories and share information,

2 which often for them is—is a form of release to, you
3 know, talk with others or let others, you know, know
4 that they're—they're sharing an experience. Thank
5 you to the city and the Department for the Aging on
6 their recent survey of informal caregivers in New
7 York City. It's a great first step in addressing the
8 need. I think that a lot of the—the—the findings
9 were, you know, reinforced some of our thinking, but
10 I think we're shocking especially the piece of many
11 of these caregivers are women. They're over 50 in
12 all categories whether they're caring for somebody
13 younger, disabled, an elder, and the financial strain
14 that—that caregiving often provides these unpaid
15 family caregivers. And, I wanted to focus a little
16 bit on that because in 2016 AARP did released a
17 report on family caregivers and out-of-pocket costs,
18 and they concluded that family caregivers not only
19 spent time and energy caring for an adult, obviously
20 who needs care, but also a significant amount of
21 money to the tune of about \$7,000 every year on
22 caregiving expenses, which on average comes out to
23 about 20% of their total income. The overwhelming
24 majority of caregivers almost four out of five are
25 incurring out-of-pocket costs at a result of—at a

2 higher than average out-of-pocket costs, and
3 especially in some caregiving groups specifically
4 Hispanic-Latino caregivers, and those that are caring
5 for someone with dementia. In addition to out-of-
6 pocket costs, many caregivers are experiencing a big
7 work strain and personal strain. I think we're
8 fortunate in New York to have paid family leave,
9 which will take effect on January 1st, but more than
10 half of caregivers in this study reported at least
11 one work-related strain, whether that's change in
12 work hours, taking paid or unpaid time off. Many
13 family caregivers are also dipping into their savings
14 and cutting back on their own personal spending to
15 accommodate for caregivers—for caregiving costs. For
16 example, roughly half are cutting back on leisure
17 spending and one in six has cut back on retirement
18 savings. This finding raises the importance for not
19 only education and assistance for family caregivers
20 but also financial assistance such as a family
21 caregiver tax credit that would help address the
22 challenges of caregiving, and this is something that
23 AARP is pursuing on the national level, the Caregiver
24 tax credit, which would allow people to claim certain
25 caregiving expenses so they can get a tax break. I

2 want to remind everyone of the important statistics.
3 I know Council Member Vallone in particular would
4 like to hear this one again. The older adult
5 population in New York City is expected to grow 40%
6 between 2010 and 2040. That's the largest growth of
7 any demographic group, and here it comes, Council
8 Member, every day 10,000 people across the U.S. turn
9 65 years of age, and this is a trend that's going to
10 continue for the next ten years. So, there's an
11 immediate concern and it's not going away any time
12 soon. So, we do have to work quickly, and we do have
13 to come up with a plan because it is not sustainable
14 to have—there's not enough caregivers to provide the
15 care to begin with, and there's not enough money in
16 the world to pay for these paid services. So,
17 keeping our unpaid family caregivers healthy and
18 happy and engaged in this work is—is critical. Thank
19 you.

20 JANE FIALKO: Council Members, on behalf
21 of SAGE thank you for holding this committee hearing
22 on unpaid caregivers. My name is Jane Fialko. I'm
23 the Care Manager at SAGE. Founded right here in New
24 York City in 1978, SAGE has provided comprehensive
25 social services and programs to LGBT older people and

2 their caregivers for nearly four decades including
3 for our five LGBT welcoming senior centers across the
4 city, and our comprehensive caregiving program, both
5 of which have been funded through the Council and New
6 York City Department for the Aging. As many of you
7 know, LGBT elders face myriad challenges associated
8 with aging: Declining health, diminished income, the
9 loss of friends and family and ageism. LGBT older
10 adults also face invisibility, ignorance and fear of
11 harassment and poor treatment. Yet, LGBT elders are
12 far more likely to live with these challenges in
13 isolation. LGBT older people are twice as likely to
14 live alone, half as likely to be partnered, half as
15 likely to have close relatives to call for help, and
16 more than four times more likely to have no children
17 to help them. As a result of these thin support
18 networks many LGBT older people have nobody to rely
19 on. In fact, nearly 25% of LGBT older adults have no
20 one to call in case of an emergency. If an LGBT
21 older adult has no legal family to rely on, who cares
22 for them? Though the statistics are troubling the
23 older LGBT population is a vibrant and resilient
24 community who have persevered by coming together and
25 caring for their own. It was LGBT people who stepped

2 up to provide caregiving support for lovers, friends
3 and even strangers who were living with HIV-AIDS. As
4 a result, social networks were expanded and
5 strengthened and survivors of that time have
6 continued to rely on these care networks. LGBT
7 caregivers make up 9% of the 34.2 million Americans
8 caring for adults over the age of 50, which is an
9 estimated 3 million people. LGBT people become
10 caregivers at a higher rate than their non-LGBT
11 peers. One in five LGBT people is providing care for
12 another adult compared to 1 in 6 in non-LGBT people.
13 Part of the reason for this is that LGBT people have
14 often been historically viewed by their siblings with
15 families as single even if they are partnered and,
16 therefore, available to take care of aging parents.
17 In the absence of people to rely on from their
18 families of origin for many LGBT people, families of
19 choice are the cornerstone—sorry—cornerstones of
20 caregiving. However, most families of choice are not
21 afforded any legal recognition or protection and
22 services—service providers may not think to inquire
23 about or include these people in their work. It's
24 important to recognize these relationships, and to
25 provide support in completing paperwork that ensures

2 the wishes of the care recipients are recognized.

3 It's common for the majority of LGBT older adults,
4 close friends and chosen family to be older adults
5 themselves, which means that many older LGBT

6 individuals rely on one another for caregiving, and a
7 large number of LGBT older adults find themselves

8 becoming caregivers. As peers and friends age, those

9 caregivers may not be able to give adequate care. To

10 better serve LGBT elders and their caregivers, SAGE

11 launched our Caregiving Program to provide a safe,

12 welcoming community to help caregivers navigate their

13 current and future needs. As they provide care for

14 loved ones, SAGE's Caregiving Program cares for them

15 and in turn helps them prepare for the time in their

16 life when they may need care. SAGE's Caregiving

17 Program offers case management, counseling, weekly

18 caregiver support groups, educational seminars and

19 online resources, self-care workshops, information on

20 benefits, respite care and supplementary support, and

21 help for caregivers planning for their own future.

22 SAGE's program is the city's only dedicated LGBT

23 caregiving program. Supporting LGBT caregivers

24 through programs and services is one of the best ways

25 for the Council to have a positive impact on the

2 lives of both LGBT caregivers and LGBT elders
3 receiving care. Thank you to the City Council for
4 your continued commitment to our city's LGBT older
5 people and caregivers. Your support has been
6 instrumental in ensuring that SAGE is there for them.

7 JED LEVINE: Thank you, Council Member
8 Chin and committee members of the Committee on Aging
9 for the opportunity to testify. I'm Jed Levine. I
10 am the Executive Vice President and Director of
11 Programs and Services of Caring Kind. It's
12 interesting that I became a caregiver this year for
13 my partner of 42 years who had open heart surgery,
14 and had about a six-month very complicated recovery.
15 I also am one of the 10,000 every day who just turned
16 65 about a week ago. So, I-I fit in a lot of these
17 categories here. Caring Kind formerly known as the
18 Alzheimer's Association New York City Chapter is on
19 the front lines every day providing a wide variety of
20 free educational and support programs including 85
21 support groups, a wanderers safety program, or 24-
22 hour help line, social work services with
23 professional counselors all designed to assist
24 caregivers, family members and persons with dementia
25 who develop, to develop methods for successfully

2 coping with this progressive and terminal illness.

3 We also train family caregivers, homecare workers and
4 other direct care workers and other professionals to
5 better care for persons with dementia. A major focus
6 for our organization's outreach to the--to the Latino,
7 Chinese, African-American, LGBT and Orthodox Jewish
8 communities and other underserved and immigrant
9 populations. We have a Queens outreach worker,
10 social worker, Bronx outreach social worker, we're
11 hiring a new Staten Island outreach social worker
12 because she was just hired by Mount Sinai for their
13 Pride of Care Program, and a Brooklyn Adventure Care
14 Specialist whose based at SUNY Downstate. We
15 estimate that about 15,000 New Yorkers come through
16 our doors every year to get information, education
17 and support. Today's hear-hearing is focused on
18 providing support to New York City's unpaid or family
19 and friend caregivers. Caring for a relative with
20 Alzheimer's Disease, and I always say this: Unless
21 you've done it, you don't really understand how
22 difficult and how demanding it is, and we know that
23 the impact of caring for a person with dementia is
24 greater than caring for somebody with other illnesses
25 not that that-- You know, I think we need to

2 recognize that. It's exhausting. It is demanding.

3 One—the task that's often done out of a deep sense of

4 love and duty and filial obligation but in many cases

5 the relationships are fractured, and there's deep

6 resentment and frustration. Usually it's a mix of

7 emotions colored by bone tiring fatigue and even the

8 most—best intentioned caregiver quickly is drained of

9 his or her emotional, spiritual, as well as financial

10 resources. The physical effects of caring for a

11 person with dementia are well documented. The

12 extensive specialized care requirements essential to

13 the person with dementia can take a serious emotional

14 and physical toll on the caregivers. We know that

15 caregivers are known to neglect their own health and

16 needs as a result of their responsibilities. This

17 burdens caregivers with physical illness, depression,

18 greater rates of fatigue and stress and increased

19 medical expenses on their own. At Caring Kind we've

20 worked with thousands of caregivers over the years,

21 and there are countless stories to exemplify the

22 impact of caregiving on one's own wellbeing. A man

23 in his 80s is caring for his wife with Alzheimer's

24 Disease. He's woken up in the middle of the night

25 every night by his frightened wife who's unsure who

2 he is, and what he's doing in her bed. When nothing
3 he says calms her down, he's forced to leave the
4 apartment, wait in the hall. Actually, this man
5 needs to go down and have the doorman ring up and say
6 Annie, it's—it's Murray. I'm here and she would let
7 him come in as if nothing happened. Greeting his
8 wife as if he just returned home from work in order
9 to distract her and get them both back to sleep. A
10 woman with Alzheimer's whose six children take turns
11 using their vacation time to rotate their caregiving
12 responsibilities in order to ensure that mom is never
13 alone and gets the care she deserves. They're never
14 able to use their vacation time for vacation. A man
15 caring for his wife with dementia with ensures she
16 makes it to her regular doctor appointments. He's
17 not a patient of this doctor, but the doctor notices
18 he's limping and asks if she can look at his leg only
19 to find a wound so seriously infected that he
20 requires immediate hospitalization. When asked why
21 he hadn't sought medical assistance, he shares that
22 he can deal with his health issues later, but his
23 wife needs him now. Presently, New York City is
24 unprepared to meet the needs of the estimated 250,000
25 persons living with Alzheimer's or other forms of

2 dementia and their caregivers. The recent survey of
3 informal caregivers by the Department for the Aging
4 makes a compelling case for caregiving services
5 across the disease and disability spectrum. Crisis
6 for Caregivers Alzheimer's Disease of New York City a
7 2013 survey and report published by Caring Kind in
8 partnership with the Office of former Manhattan
9 Borough President Scott Stringer shows the
10 significant impact of Alzheimer's Disease and related
11 dementia's on New York City and the inadequate
12 support or awareness of support provided to dementia
13 caregivers. Our findings revealed the following, and
14 they're remarkably similar to the current—the most
15 recently finished survey by the department.

16 Caregivers spend significant amount of time providing
17 unpaid care to their family member or friend with 40%
18 spending as many or more than 40 hours, a full work
19 week providing unpaid care. A majority of
20 respondents missed at least one day of work due to
21 caregiving. 17% missed 21 days or more of work.

22 Survey respondents are deeply dissatisfied with the
23 level of services and support provided to persons
24 with Alzheimer's Disease including daycare and
25 nursing home care and home care. More than 95% of

2 respondents believe there needs to be a citywide plan
3 to address Alzheimer's Disease and related dementias
4 both in persons with the disease and their
5 caregivers. Persons with dementia, their family and
6 caregivers face unique challenges when navigating New
7 York City services. It's critical to look at the
8 experience of caring for a family member with
9 dementia through the lens of that caregiver, whose
10 often emotionally and physically stressed and doesn't
11 have the time or energy to search for assistance. We
12 also know that many families are dependent on the
13 help of paid homecare workers many of whom have had
14 little or no training in dementia care. We've been
15 conducting a nationally recognized dementia care
16 training program for over 25 years, and have learned
17 a lot about how to improve knowledge, change practice
18 and improve the care of persons with dementia, as
19 well as providing the workers with a sense of pride
20 and as data show us maximize the chance that they
21 will stay in the field of dementia care. To increase
22 and improve access to New York City's senior and
23 caregiver services, Caring Kind recommend the
24 following action items: The New York City Council,
25 Department of Health and Mental Hygiene, and

2 Department for the Aging should consider making
3 information on aging related health conditions such
4 as Alzheimer's Disease and Dementia more accessible
5 through web and print material-media. For example,
6 the New York City Department of Health, Mental Health
7 site should list Alzheimer's Disease on it Health
8 Topic A to Z page where it does not exist. One has
9 to—I'm not quite sure where it exists on that
10 website. We had a hard time finding it. New York
11 City should also produce a public awareness campaign
12 to educate residents on the signs of Alzheimer's
13 Disease, and where to turn for help including
14 available services for caregivers. New York City
15 should promote the Department for the Aging's
16 Alzheimer's and Caregiver Resource Center and Caring
17 Kind's 24-Hour Helpline. We're so pleased with the
18 news that the city is funding caregiver Respite
19 Services at the \$4 million, which we talked about
20 consistent with the legislation. Providing
21 supportive services and access to respite for the
22 caregiver is key to maintaining his or her own
23 wellbeing, and that of the person with Dementia.
24 This includes daycare, homecare or temporary
25 placement to allow the caregiver to attend to their

2 own health, to daily chores, get their hair cut,
3 attend a support group, education program or simply
4 have some down time. We've been providing respite
5 vouchers for the past 20 years, and we've been very
6 successful in doing that, and I would offer that we
7 can be a resource to help spend that \$4 million and
8 get that—some of that money into the hands of
9 caregivers who deeply need it. So, we really
10 appreciate the commitment of the Committee on Aging
11 and Chair Margaret Chin to improving the lives of New
12 York's family caregivers. Caring Kind stands ready
13 to provide expert guidance and assistance in
14 considering these matters and in implementing the
15 respite and other caregiver programs. Thank you.

16 CHAIRPERSON CHIN: Wow. Thank you very
17 much for all your testimony and your partnership in
18 doing this work. We're really looking forward to
19 working together. I know that all of you helped
20 tremendously advocating, you know, for the \$4 million
21 for care—the caregiving services. So, in earlier,
22 you know, in the questions that—that we had with the
23 Administration and with the Commissioner, going
24 forward do you have a projection or like how much

2 more funding would you really continue to advocate
3 for? [pause] Anyone?

4 CHRIS WIDELO: A lot. [laughter] Well,
5 and—and I—yes, I think a lot, right. So, does money
6 solve all problems? No, but I think in the case of
7 aging where we have one of the smallest budgets, less
8 than a half a percent of the overs city budget is
9 dedicated to the most rapidly aging population. I
10 think we need to right size the DFTA budget and also
11 look at what other agencies are doing, and how they
12 could be instrumental in this conversation beyond
13 just the Department for the Aging. The Aging
14 Coalition has put together sort of a five-year plan.
15 I can share that again so you have a sense of what
16 we're looking at, but right in that money that we
17 allocated, we were able to address some of the
18 waitlist issues with homecare, and—and case
19 management, which are a part of that caregiving
20 continuum, right. They—they are providing care and
21 giving relief to those caregivers, but we know that a
22 waitlist starts the minute that it's cleared because,
23 you know, we're just addressing the current need not
24 the need that's actually coming down the road. And I
25 think many—we know that many people are just not, you

2 know, counted because they either don't know about it
3 or they're discouraged because they know that they're
4 not going to get hours. So, I think we can kind of
5 give you a sketch and provide it to you. We can
6 email you or—or drop it off to your office sort of
7 what we see in the future, but I—I think you can
8 guarantee that come January 1st, we'll be, you know,
9 we'll be talking together about, you know, what we
10 need in this coming year—fiscal year.

11 CHAIRPERSON CHIN: Thank you. Yes, Jed,
12 in your testimony, you were talking about 15,000
13 people get services through Caring Kind.

14 JED LEVINE: Those are the people who
15 actually come to our doors. There are many more who
16 actually call the Helpline. We're getting about I
17 would say 850 to 1,000 calls a month. We also have
18 about I think it's over 100,000 people who are on our
19 electronic newsletter mailing list. So, they're
20 getting information that way. We have about 29,000
21 people enrolled in our Medical Alert or a safety
22 program, which we do in partnership with the—with
23 NYPD when somebody goes missing whose—who has
24 Alzheimer's or related Dementia. So, you know, we—
25 it's been hard to estimate the actual number of

2 individuals that are served through Caring Kind that
3 I would—and should say it's probably about 50,000
4 individuals who are served across the city.

5 CHAIRPERSON CHIN: So, what is the cost
6 to you, I mean your budget to serve the--

7 JED LEVINE: [interposing] Our—our budget
8 is currently I'd say about \$8.5 to \$9 million, and
9 close to 90% of that is privately supported. We get
10 very little government support. We have a state-
11 subcontracted on a state grant for Alzheimer's
12 support and as you know, the Governor made the
13 largest investment in Alzheimer's care and support in
14 the country by adding \$25 million, I think it was
15 three years ago, to provide support services across
16 the state, and we also were a subcontractor on an NYU
17 grant as part of that Alzheimer's support initiative.
18 We have an under-served grant where we provide
19 services and allows us to provide more extensive
20 services and grants.

21 CHAIRPERSON CHIN: And when you were
22 talking about the—the respite voucher--

23 JED LEVINE: Uh-hm.

24

25

2 CHAIRPERSON CHIN: --how many people
3 served--that you served with that, and how much is
4 the--is the vouchers?

5 JED LEVINE: The vouchers go up to
6 \$2,000, so many people use a lot less than that, and
7 it's really seen as a bridge program. So, to provide
8 people a break and to get them services while they
9 were applying for more long-term care services, and
10 the long-term care--accessing long-term care is so
11 complicated and difficult, and hard for people to--to
12 negotiate, and it takes several months for somebody
13 to get on Medicaid. Where perhaps there's social
14 adult daycare where they can get on Medicare through
15 that. I don't have the figures in my--with me, but I
16 can get back to you about the number of the
17 individuals that are served. I think our budget for
18 the Respite Program last year was about \$150,000.
19 So, you know, it's--but not every--with the maximum of
20 \$2,000 with each individual, and that on our social
21 work--social workers work with those families in
22 applying for the grant, accessing Respite Services.
23 We have a Respite Specialist who can talk about what
24 the--what Respite is, why it's important, how to
25 access it, and through our community partners who

2 provide the respite because we don't provide the day
3 care, we don't provide the home care, we're able to,
4 you know, help those individuals get a break. Many
5 people don't recognize that they need that break, and
6 then once they do, then they can start doing the
7 long-term care planning that they would like—that's
8 required with a disease like Alzheimer's.

9 CHAIRPERSON CHIN: Great. Thank you.

10 COUNCIL MEMBER VALLONE: Just—just wanted
11 to thank you each one of you. It's a pleasure with
12 Margaret and I serving with the organizations. You
13 carry your hearts on your sleeve with your stories,
14 and we listen to every one of them. Very compelling
15 and I think that's why you see our emotions up here
16 no matter who testifies because it's really never
17 enough. We need to do more, but when you tell those
18 stories, we are listening, and we're feverishly
19 writing down legislation ideas, and budgeting ideas,
20 and that's why I think Chair Chin brought up your
21 respite voucher because as she was asking the
22 question, I was writing it down because so many of
23 the services are so individualized and specific of
24 the particular person calling. There is no omnibus
25 plan, but some type of maybe credit for someone for—

2 to be used as they need fit. Not to be abused, but
3 that's where we would have some type of plan in
4 place. That's where I was thinking of some type of
5 credits for folks whether it was transportation,
6 whether it was services, whether it was respite care,
7 whether it was medical. I think if you can get
8 additional information on that respite voucher, maybe
9 we can kind of piggyback or match or work out
10 something to expand that.

11 JED LEVINE: That would be great. I will
12 get you that information. We—we—our Respite Program
13 is based where we provide—where we pay the provider.
14 We—we—we very rarely will pay a caregiver.
15 Occasionally, they've had some out-of-pocket
16 expenses, which they can then document. We will
17 reimburse, but most often it's paid where they get
18 access to this money, but it has to be used at a
19 licensed provider.

20 COUNCIL MEMBER VALLONE: Well, those out-
21 of-pocket expenses—expenses that are documented, I
22 think that would be a great way to start. You know,
23 this way people would have a—it's kind of like how
24 most of our City Council programs. It's a spend-
25 down. You have to show you used it. So, I think

2 that would be a great way to minimize any type of
3 fraud that someone might want to use, but actually
4 use it for a good legitimized reasons, but I think
5 that's a great start. Thank you always for—for all
6 four of you groups and the other organizations that
7 are out here for being part of this hearing today.

8 JED LEVINE: Thank you.

9 CHAIRPERSON CHIN: Council Member Rose.

10 COUNCIL MEMBER ROSE: Thank you. I want
11 to start with a big thank you. As a person who found
12 themselves in—in that situation being a part of the
13 sandwich generation, and—and finding my mom, you
14 know, having Alzheimer's, it was probably the most
15 difficult time in my life being torn between how to
16 care for her, keep her safe, and—and when it was time
17 to make referrals to other agencies. So, I want to
18 thank you for the work that you do, and most of you
19 provide direct care and referrals, right? Well, let
20 me rephrase it. First, I want to thank you for the
21 Staten Island Social Worker, and I found as an unpaid
22 caregiver that there was no one who trained me or
23 educated me about how to care for my mom. No one
24 explained some setting to me, how to de-escalate a
25 situation, and—and absolutely it was very difficult.

2 As someone who is used to providing information for
3 people, I found it very difficult to get the
4 information that I need. No one talked about the
5 progression, and so are any of you providing sort of
6 that hands-on training and education of-of
7 caregivers.

8 JED LEVINE: Uh-hm. Well, we certainly
9 are. We do run a program called *Understanding*
10 *Dementia* for families that are new to it, which we're
11 doing also on Staten Island and all the boroughs
12 actually, which talks about the progression of the
13 disease, which talks about what's really available in
14 terms of treatment for management of the symptoms.
15 The fact that this is a medically incurable disease,
16 and also the role that family members need to start
17 taking and identifying themselves as caregivers, and
18 then families can attend our—we have a 10-hour Family
19 Caregiver Workshop, which we're offering now in
20 English, Spanish and in Mandarin and Cantonese, and
21 offering those that really is a skill building
22 program to teach the skill of dementia care, and how
23 to communicate best, how to engage the individual,
24 and the importance of self-care so that you can
25 continue to provide this really important care, and

2 at the same time, we also, you know, partnered that
3 with the support groups where families can really get
4 that connection. Families tell us that that's a
5 lifeline for them. That's what kept their head above
6 water because they were able to meet with other
7 family members who were going--other people who were
8 going through the same thing, and are understood in a
9 way that they're not understood in any other arena of
10 their life. So--and then also working with the
11 social work staff to access all of the long-term care
12 entitlements. Most of our families are going to end
13 up on Medicaid because Medicaid becomes the payer for
14 long-term care whether it's homecare or eventually
15 residential care.

16 COUNCIL MEMBER ROSE: Is there any
17 special qualifications for how someone qualified for
18 the Respite Voucher with a- ? I just have to say I
19 think it's so--such a critical part of caregiving--

20 JED LEVINE: [interposing] Yeah, we--

21 COUNCIL MEMBER ROSE: --that there is the
22 ability for them to have respite--

23 JED LEVINE: [interposing] They can--

24 COUNCIL MEMBER ROSE: --and find time to
25 take care of themselves.

2 JED LEVINE: Absolutely and I think
3 there's—we don't—we don't have a financial—we do a
4 financial screen, but there's really—it's—it's almost
5 everybody is available to it who—who call if they
6 need to call our helpline and ask to speak about the
7 grants. And then we can do an assessment of what
8 their caregiving situation is, make sure they live in
9 the city, make sure the situation is a dementia
10 situation. Those are the requirements that they live
11 in New York, and that they are a caregiver for a
12 person with Alzheimer's or another kind of dementia,
13 and also that they are willing to look at long-term
14 plan because this is, you know, it's \$2,000 does not
15 go that far actually, and—but it's used as a planning
16 tool as a bridge, as I said.

17 COUNCIL MEMBER ROSE: So, is that a one-
18 sort of like a one-shot situation? Over the course
19 years of the disease, I might find I need a respite--

20 JED LEVINE: [interposing] Right.

21 COUNCIL MEMBER ROSE: --more than one
22 time, and what if I don't want to look at long-term
23 care. I'm not at that place yet--

24 JED LEVINE: Uh-hm.

2 COUNCIL MEMBER ROSE: --because, you know,
3 that's sort of a process that evolves.

4 JED LEVINE: Right. So, I mean long-term
5 care includes homecare and daycare and overnight
6 respite, and then eventually residential, you know, a
7 permanent long-term care. So, in our program and we
8 partner with many of the -the DFTA funded Respite
9 programs and-and work together so that we can
10 maximize the dollars, and also work with many of the
11 state funded Alzheimer's assistance programs that
12 exist in-in the city. So, people have up to a year
13 to use their-their voucher, and then because of the
14 limited-we have limited dollars. We do not give a
15 grant the next year, but the following year if the
16 need still exists, we'll be able to offer that, but
17 if we had more money, we could offer it every year.

18 COUNCIL MEMBER ROSE: Okay. So that
19 sounds like an ask, Chair. There will be some
20 financial ask made. Do you work with-in the case of-
21 - Well, let me go back. A long time ago, when I
22 worked for the Health and Hospitals Corporation, at
23 Seaview Hospital we had a Respite, you know--

24 JED LEVINE: [interposing] Right the Day
25 Program.

2 COUNCIL MEMBER ROSE: --facility, and
3 there was a cost, sort of per-day cost, and you could
4 use it as needed. Do you use a specific facility or-
5 -

6 JED LEVINE: [interposing] No, no, that's
7 up to the individual to—we can help them. We can
8 give them information about what's available in their
9 community and it's up to them to use the one that's
10 most convenient or the one that's best going to meet
11 their needs. So, we don't have any particular
12 provider. No. We work with all of the daycare
13 programs, other homecare agencies, and, you know, and
14 as-as Dr. Finley said, sometimes it's helping
15 somebody pay for incontinent supplies because their-
16 their Medicaid ran out. They didn't have enough
17 money that month to pay for that, or sometimes it's
18 paying for food. Sometimes it's paying—helping the
19 family member pay rent because a daughter had to stop
20 working for two weeks, didn't get that check, and
21 she's falling behind and in order--

22 COUNCIL MEMBER ROSE: Right.

23 JED LEVINE: --to prevent homelessness.
24 So, you know, that—that goes into our special
25 assistance fund. So, it's not just the respite funds.

2 So, we have other kinds of limited resources to help
3 families so that they can continue to provide the
4 care that they need to.

5 COUNCIL MEMBER ROSE: Thank you so much.

6 JED LEVINE: You're welcome. Thank you.

7 COUNCIL MEMBER ROSE: Thank you, Chair.

8 CHAIRPERSON CHIN: Thank you. Thank you
9 again to this panel for your great work. We look
10 forward to continue working with you. Thank you.

11 FEMALE SPEAKER: Thank you.

12 CHAIRPERSON CHIN: We're going to call up
13 the next panel. Marcia Friedlander; Maggie
14 Orenstein, New York Caring Majority; Bobbie Sackman;
15 and Ian [background comments, pause] Mackowitz.
16 [background comments] Magerkurth. Okay. [laughs]
17 Ian. Okay Alzheimer's Association. [background
18 comments, pause]

19 CHAIRPERSON CHIN: Oh, you have to give
20 it to the sergeant. [background comments] Okay, you
21 may begin. Bobbie, are you with another group this
22 time? [laughs]

23 BOBBIE SACKMAN: I never go away. My
24 name is Bobbie Sackman, and I'm testifying today on
25 behalf of Jews for Racial and Economic Justice, and

2 part of the Caring Majority Coalition. I am the
3 former Director of Public Policy at Live On New York,
4 and I'm glad to be able to continue to advocate for
5 the same issues I, you know, spent my career on, and
6 it's—it's good to see you. So, I'm just going to hit
7 some highlights. I don't have any formally written
8 testimony. The New Yorkers Majority Coalition—Carin
9 Majority Coalition, which you've now been given the
10 sticker for and you'll hear more about, is a
11 statewide coalition of homecare providers, care
12 recipients such as seniors and people with
13 disabilities and family caregivers. So, really for
14 the first time we have all aspects, all sides of the
15 need for long-term care coming together, which to my
16 mind is very exciting, and they actually approached
17 us about a year ago and they want to advocate for the
18 EISEP Program on a state level. Well, nobody outside
19 our world even knows EISEP exists. So, and this is
20 for people above Medicaid. So again, that's really
21 exciting, the goal being universal long-term care
22 across the state. Also, as we've seen today, we're
23 really just at the tip of the iceberg. So, there
24 really are thing the City Council can to do help, and
25 I'm going to get to that in a moment. The other

2 thing I do want to point out is when you bring a
3 coalition like this together, I really think it's
4 very pioneering, and that for the first time we will
5 have—it's intergenerational. It is extremely
6 diverse, you know, because, you know, the workforce,
7 the care recipients and the families, it—it is—it is
8 addressing income inequality head-on. It is just
9 brining together in a way all these issues that are
10 out there. So, one of the thing I'm going to ask is
11 as we move into the new year, and I know there's
12 going to be new committees, new committee chairs, but
13 there will still be a woman's caucus. There will
14 still be a progressive caucus. There will still be
15 an aging committee that these issues really get
16 highlighted there and—and worked on. There was a
17 speaker's forum that AARP did just a few nights ago,
18 and two of the candidates when asked said that, you
19 know, we're basically providing services in this
20 field on the backs of a low paid workforce, and they
21 used the word abusive, and it is abusive. And again,
22 part of what the Caring Majority Coalition wants to
23 do is how do we get fair compensation for homecare
24 aids, for people in the workforce from senior
25 centers, NORCs, et cetera? When we watch horror—in

2 horror at the deportation of immigrants that's who
3 the homecare aids are largely. They are immigrants,
4 and so, there's an impact of different policies on
5 this field. There was also a law passed recently in
6 the last number of months that assigned into law I
7 guess that made caregivers a protected class in work
8 discrimination. It might be interesting for the
9 committee to look at how is that working? Well,
10 first of all, does anybody know about it, but also
11 how does it work, and is it—is it accomplishing
12 anything? So, I just want to just a couple of
13 specifics, you know, and—and I should have started by
14 thanking you because the \$4 million was a huge win.
15 It doubled the money for the city. We all know how
16 long that took, and having this survey again we—we
17 did all know the results of it, but it's in writing,
18 and—and now the city—it gives us something to push
19 the city on. So the Statewide Coalition there's a
20 budget ask out there on a state level. So, what
21 could be helpful is that (1) City Council members,
22 and we will share it with everybody, could go to
23 their—their colleagues, their local state Assembly
24 members and senators from your district, and make
25 this a priority. City Council can make this a

2 priority in an Albany, you know, legislative/budget
3 agenda. Push the Mayor who is now finally talking
4 about seniors first in his housing agenda, which we
5 applaud him on, but how long does that take, and so I
6 think you year of the senior is not going to stop and
7 it has tentacles. Those things always do and I-I
8 applaud you for that. So, how do we get continued
9 support, and one of the things, and I know, you know,
10 you've done this before is a City Council briefing
11 that could both brief on this study, which I think
12 will be great, and also maybe there could be a piece
13 in there that talks about what is the--the Statewide
14 Caring Majority Coalition and how could City Council
15 help. Obviously down the road perhaps a resolution
16 of some kind and, of course, you know, city money.
17 You know there will be a continued waitlist. How do
18 we continue to grow this--this pot of money? There--
19 there was a headline in the New York Times sometimes
20 early--sometime earlier this year. I think it might
21 have been an editorial, and it said that the best
22 long-term care insurance there is, is having a
23 daughter. I mean that was literally the headline,
24 and probably I'd throw in daughter-in-law. We all
25 know that, and--and that cannot continue, and that's

2 what we're hearing today about family caregivers.
3 They are mostly women. Not all, but they are mostly
4 women, and—and we're on—we're doing this—society is
5 taking, you know, advantage on the backs of women.
6 I—sometimes I think what would it be like without all
7 the women in this society? A lot of things would
8 fall apart that we don't give credit to. So, that's—
9 that's really, you know, most of what I want to say
10 today, and I think we have a great opportunity with
11 the—the majority. I'm sorry, Caring Majority
12 Coalition and, you know, we could talk further about
13 it. But again, thank you for all the work you've
14 done over the years because I think it's beginning to
15 see fruition. Thank you.

16 MAGGIE ORNSTEIN: Good afternoon, Council
17 Member Chin. Thank you so much for this. It's a
18 long time coming and I really appreciate the support.
19 I'm Maggie Ornstein. I'm pleased to be here today to
20 testify on the importance of support for the millions
21 of unpaid caregivers in New York City who provide 80
22 to 90% of all long-term care, an estimated 90% of
23 them providing care without outside assistance. I
24 applaud the city for recognizing and dedicating
25 funding to support—to provide essential supports for

2 New York City residents. This invisible yet vital
3 work supports the lives of others on a daily basis.
4 It's hard to follow Bobby, but I'm also here with the
5 New York Caring Majority Coalition, and I won't
6 reiterate what she has said, but support all of the
7 recommendations. In 1996, at the age of 49, my
8 mother had a cerebral aneurism rupture, which left
9 her in a coma and minimally conscious state and on
10 life support for nearly five months. I also took
11 care of my grandmother, who lived with us and was
12 approaching 90 at the time. I was 17 years old. At
13 that time my life was transformed into one completely
14 dedicated to getting her better. She had to relearn
15 how to walk, talk, and speak, and I had to learn to
16 navigate a brutally difficult bureaucracy. I had no
17 desire to become and advocate for a more just
18 healthcare system. However, it became immediately
19 apparent that this was required of me for my mother's
20 very survival. Over the years I've cared for
21 multiple other family members all of whom were born,
22 lived and died in New York city. While my caregiving
23 career is extreme, it is not unique and I urge you to
24 consider the unidentified young caregivers, children
25 under the age of 18 who provide care to family

2 members and who are present throughout the New York
3 City School System. They need support, too, and
4 often eligibility requirements create barriers to
5 accessing services. When I was in my earl 20s, and
6 looking for support, my grandmother was in her 90s,
7 not on Medicaid, and my mother was only in her 50s,
8 and so ineligible for services. As I looked for
9 support, I was turned away because neither of the
10 people I was caring for fit the eligibility
11 requirements. The result was that I was invisible
12 and abandoned by the very system in place to help me.
13 So, just a few points to consider in the development
14 of caregiver supports, and I say supports are not
15 services because I think there are a lot of other
16 ways to potentially help people. So, the caregiving
17 triad, caregiver, you know, care teams ideally
18 involve family caregivers and paid care workers
19 along with the care recipient, and so consistency in
20 the paid care first, which means investing in
21 training and higher wages to recruit and train care
22 workers is essential. Without this workforce, family
23 caregivers' jobs are that much more difficult. To
24 improve upon services they must be available to
25 chosen families. This was mentioned earlier. We

2 must broaden our definitions to be more inclusive of
3 the myriad caregiving situations, which exist, and
4 they must serve the family unit, not only the patient
5 but care receiver. Trauma-informed services, which
6 take into account the trauma faced by families when
7 there's a catastrophic medical event would be
8 valuable to family caregivers who are often facing
9 the most difficult times of their lives. And lastly,
10 I would ask that—that we all consider housing
11 difficulties from the perspective of family
12 caregivers. In order for long-term community-based
13 supports and services to work, there must be a home
14 available for those services to be provided them, and
15 that's often really taken for granted. There's no
16 question about who's providing that household and
17 it's often the family caregivers who are struggling
18 to pay for housing and also carving out space for
19 themselves in homes that have become both work places
20 for homecare workers and sites of care for care
21 recipients. Housing subsidies for families are
22 programs similar to the Senior Citizen Disability
23 Rent Increase Exemptions could be expanded to include
24 caregivers. The Caregiver Rent Increase, CRI and/or
25 caregiver property tax reductions can help ease the

2 financial burden of increasing costs of housing in
3 the city. And finally, changes to zoning could
4 improve living conditions for people who want to keep
5 family members at home, but need more space to do so.
6 So, allowing accessory dwelling units for families
7 who have care recipients and family caregivers living
8 together is a creative solution in the outer
9 boroughs, which could ease the rent burden, and allow
10 people to stay home longer than they otherwise would
11 be able to, and this is happening in other cities,
12 and should be looked at here. So, my home right now
13 is very crowded. In addition to my mother who is now
14 in her early 70s, I have a neighbor who's recovering
15 from a fall living with us, and we recently added
16 twin foster children to our home. So, if I could
17 convert our garage into a living space, as is allowed
18 in other cities, the tensions around space would be
19 greatly reduced improving the conditions of our daily
20 lives, and this wouldn't need to cost much money to
21 the city. It would help with housing and reducing
22 caregiver burdens around space, which is a common
23 complaint of caregivers, and just to contextualize,
24 there were statistics thrown out, and there are my
25 own statistics, but for context, I provide 96 hours

2 of care to my mother every week that if I got sick
3 tomorrow or had to go move somewhere else, would be
4 provided by Medicaid. And so that equals close to
5 \$90,000 a year just as my inputs to the system, and
6 so, if we looked at caregivers and somehow figured
7 out how to put a small percentage of that back into
8 families' pockets, it would go a long way in--in
9 helping people provide the care that they do.

10 MARCIA FRIEDLANDER: (coughs) Good
11 morning to all distinguished members of the Committee
12 on Aging, Commissioner Corrado, Commissioner,
13 distinguished staff of the New York City Department
14 for the Aging, and community colleagues. Thank you
15 for conducting this hearing today. My name is Marcia
16 Friedlander. I'm the Clinical Director of Services
17 Now for Adult Persons Caregiver Program, SNAP, which
18 is for short is dedicated to addressing the needs of
19 the ethnically and economically diverse senior
20 population in Queens. The agency is home to both
21 innovative and neighborhood senior centers as well as
22 the virtual senior center for those seniors who would
23 like to participate incentive programs an activities,
24 but [background comments] Okay, but are physically
25 unable--thank you--unable to attend the senior centers'

2 transportation, case management, home delivered
3 meals, friendly visiting as well as SNAP's newly
4 established social adult day program, which is only
5 like two weeks old, I'm glad to report—are all part
6 of the continuum of services, which SNAP provides to
7 the senior community. The Caregiver program of SNAP
8 has been providing both emotional, financial and
9 respite support to informal caregivers since January
10 2003. In the past 14 years, SNAP has gained a
11 significant amount of experience and knowledge
12 working with caregivers in Queens. So, we would like
13 to share our thoughts with you this morning.

14 Individuals aged 85 years of age and older continue
15 to be amongst the fastest growing in the elderly
16 population. This cohort of advanced age individuals
17 creates an increasing demand for loved ones to
18 become actively engaged in their care. As a result,
19 support for caregivers in this role has become vital
20 in regard to helping older individuals age in place
21 and avoid unwanted and costly institutionalization.
22 From experience, SNAP has recognized that most
23 caregivers contact our office when they are already
24 feeling overwhelmed. Individual respite tends to be
25 the most frequently requested service with caregivers

2 wanting a home health aid to come to the care
3 receiver's home. As caregivers become familiar and
4 comfortable with both the program, and the staff,
5 they also become open to participating in other
6 services such as counseling support groups and
7 educational workshops. Similar to the way Meals on
8 Wheels often opens the door to other case management
9 assistance, SNAP finds that Respite is the concrete
10 service that opens the door to emotional support for
11 caregivers. At first, caregivers may believe that
12 Respite service is all they need to manage. They
13 often come to realize that by taking advantage of
14 both Respite and emotional services, they are better
15 able to balance the myriad of responsibilities they
16 face in their caregiving role. The majority of
17 SNAP's caregiver clients are women, as we established
18 here today, who are in the position of juggling both
19 work and caregiving. Adult children caregivers are
20 often forced to compromise their work life in order
21 to meet the needs of their elderly parents and/or
22 relatives. Women and minority caregivers are most
23 likely to reduce work hours or leave work completely
24 to care for an older adult. Creating ways of
25 supporting these adult children caregivers so that

2 they may remain in the workforce and effectively
3 balance both work and caregiving responsibilities is
4 an essential part of caregiver support. The new paid
5 New York State Family Leave Act will go into effect
6 in January 2018, and will help to promote this
7 balance for working caregivers in the future.
8 However, we must consider additional ways of
9 providing economic stability and policies that
10 support caregivers in the workforce. This will
11 benefit both employers and employees. Employees will
12 be able to continue working and not have to leave the
13 workforce earlier than they would have planned, and
14 employers will be able to keep experienced workers on
15 staff. Helping caregivers continue to contribute
16 financially toward their future without having to
17 leave the workforce sooner, benefits the caregiver
18 into retirement. SNAP has also recognized that most
19 caregivers need affordable legal services with access
20 to legal information and guidance. These caregivers
21 are already paying out of pocket caregiver expenses.
22 Many have difficulty covering their own costs while
23 also dealing with expenses from their loved ones.
24 Private elder law attorneys are unaffordable for many
25 people, and law schools or affordable legal services

2 often have wait lists and/or are limited in what they
3 do. Another area of concern in regards to caregiving
4 is related to reaching diverse communities with
5 caregiver support. Cultural differences often act as
6 barriers to accepting help, education for staff,
7 caregivers and care receivers is vital if we are to
8 reach diverse populations. So start with, staff must
9 grow in awareness and sensitivity toward cultural
10 nuances. Caregivers from diverse cultures may feel
11 reluctant to accept assistance as they fear their
12 older loved ones reacted to seeking help form the
13 outside. Going outside of the family is often
14 frowned upon and feared within these communities.
15 Education in this regard will take time and effort on
16 the part of professionals if we are to make a
17 difference in these communities. Helping caregivers
18 identify as such continues to play a role in their
19 seeking services. Identifying where to find support
20 continues to be a challenge for clients and programs
21 alike. Staff is limited in terms of resources,
22 budgets, and time for the kinds of outreach necessary
23 to make caregiving a household phrase. A public
24 awareness campaign would help make caregiving a
25 familiar term and would begin to make reaching out

2 for assistance and acceptable practice. Finally, in
3 terms of the professionals who work in SNAP's
4 Caregiver program, it should be mentioned that SNAP
5 staff has either been with the program since its
6 inception or has been with it for multiple years.
7 These professionals bring a wealth of experience and
8 dedication to the team and are an integral part of
9 creating a quality program. They are able to
10 recognize the value of the work that informal
11 caregivers provide and are able to help these people
12 on multiple levels. Salaries for these committed
13 workers should reflect the professionalism that is
14 needed to carry out the program services. These
15 workers have provided services to caregivers for
16 years with out the benefit of salary increases as
17 budgets do not allow for it. Whenever additional
18 funding is given, salary needs for existing staff are
19 never part of the equation. In addition, SNAP's
20 Caregiver Program is fully staffed by women, many of
21 whom have been caregivers or will be caregivers in
22 the future. What message do we send the staff when we
23 discuss the importance of helping women caregivers
24 remain financially viable while at the same time
25 avoid any discussion of remuneration for

2 professionals providing services to these caregivers.
3 Caring for clients, families and staff are all part
4 of a balanced system that works well for all. SNAP
5 recognizes and appreciates the focus that government
6 has placed on alleviating the stress of New York City
7 caregivers. We look forward to continuing in our
8 work together, and thank you for the opportunity to
9 share today.

10 CHAIRPERSON CHIN: Thank you. Is SNAP
11 one of the ten--

12 MARCIA FRIEDLANDER: [interposing] Yes.

13 CHAIRPERSON CHIN: --providers that are
14 contracted by DFTA?

15 MARCIA FRIEDLANDER: Yes.

16 CHAIRPERSON CHIN: Okay.

17 IAN MAGERKURTH: [off mic] Good
18 afternoon. [on mic] Good afternoon. My name is Ian
19 Magerkurth, and I'm the Director of Government
20 Affairs for New York State for the Alzheimer's
21 Association. I appreciate the opportunity to testify
22 today on this oversight hearing on supporting unpaid
23 caregivers. I would like to begin by applauding you,
24 Chairwoman Chin, together with Speaker Mark-Viverito,
25 and the entire City Council for their commitment and

2 support to the city's aging community, and for
3 working to enact Local Law 97 of 2016, which led to
4 the recent findings in DFTA's 2017 Survey of Informal
5 Caregivers in New York City. The Alzheimer's
6 Association is the leading voluntary help
7 organizations Alzheimer's advocacy, research and
8 support. Our mission is to eliminate Alzheimer's
9 Disease through the advancement of research to
10 provide an enhanced care and support for all
11 affected, and to reduce the risk of dementia through
12 the promotion of brain health. We provide education,
13 care and support to New Yorkers affected by
14 Alzheimer's and other dementias through our free in-
15 person and online programs for caregivers,
16 professionals and the public on a wide range of
17 topics such as diagnosis, early warning signs, and
18 the need for caregiver support and respite. We have
19 a diverse and multi-lingual staff of specialists and
20 master level clinicians that can work with New
21 Yorkers in need in person or over the phone through
22 our free 24/7 Health Line. We also advocate for the
23 needs and rights of those facing Alzheimer's Disease,
24 helping to educate policymakers on the Alzheimer's
25 crisis and engage with them in our efforts to fight

2 the disease. I want to use this opportunity to
3 report on the—to focus on the findings of the recent
4 report in regard—in regards to adults caring for
5 family members age 60 and over including adults with
6 Alzheimer's Disease or other dementia. There is no
7 one-size-fits-all formula when it comes to
8 Alzheimer's care. Needs change at different stages
9 of the disease and each family situation is unique.
10 Deciding on who is best suited for providing long-
11 term caregiving tasks can be a tough decision.
12 Approximately 390,000 individuals in New York State
13 have Alzheimer's and more than one million New
14 Yorkers provide unpaid care for the people with
15 Alzheimer's and other dementias. Caring for those
16 loved ones can take a severe emotional, physical and
17 financial toll on the individuals providing it. At
18 the Alzheimer's Association, we felt—we faced this
19 public health challenge head-on by providing
20 interventions that address the continuum of care. As
21 I mentioned, more than one million New Yorkers
22 provide unpaid care for people with Alzheimer's and
23 other dementias. Fifty-nine percent rated their
24 emotional stress as high or very high. Additionally,
25 about 40% of family caregivers suffer from

2 depression. Caregivers experience work-related
3 challenges when they begin caregiving. Fifty-four
4 percent had to go-leave late or leave early and 15%
5 had to take a leave of absence. On average, care
6 contributors lose more than \$15,000 a year in annual
7 income as a result of reducing or quitting work to
8 meet the demands of caregiving. By 2030, the segment
9 of the population age 65 and older will increase
10 substantially, and older Americans will make up
11 approximately 20% the total population. As the
12 number of older Americans grows rapidly, so, too,
13 will the number of people with Alzheimer's Disease.
14 The progression of Alzheimer's Disease is slow, and
15 debilitating and as such contributes to the public
16 health impact of Alzheimer's Disease much of the time
17 with the disease is in disability. As such, the
18 growing elder population as well as the growing
19 population of New Yorkers will rely on the critical
20 services provided by the Department for the Aging and
21 its city funded contractors. We applaud DFTA for its
22 thorough and comprehensive survey including care-
23 stakeholders and the development, data collection and
24 interpretation of the survey's finding. On the
25 availability of services, the survey found that many

2 caregivers over age 60 between 73 and 74% did not
3 know about the services available to them. On
4 Respite. For all caregiver groups, Respite was among
5 the top four services in demand but is also among the
6 services with high levels of unmet need. Caregiving
7 is demanding and it's normal to need a break.

8 Respite services benefit the person with Dementia as
9 well as the caregiver providing temporary rest from
10 caregiving while the person with Alzheimer's
11 continues to receive care in a safe environment.

12 Using respite services can support and strengthen
13 one's ability to be a caregiver, as well as provide
14 time to relax, socialize, take care of errands such
15 as shopping, exercising, things such as getting a
16 haircut or even going to the doctor. Another finding
17 in the report was on ethnic communities and we found
18 the key limitation of the Caregiver Study was that
19 the sample of caregivers of older adults are mostly
20 black and white and were primarily with 90 and 92%
21 English speakers. New York City has by far the
22 largest immigrant senior population of any U.S. city.
23 According to the Center for an Urban Future, as of
24 2015, 49.5% of New Yorkers age 65 and older are
25 foreign born and by 2020 immigrant seniors will be

2 the majority. Today, there are now 23 out of the 55
3 census defined neighborhoods citywide where the
4 majority of seniors are immigrants. Many seniors and
5 their caregivers have limited English proficiency,
6 which impacts their ability to seek and receive
7 services. As such, the Department for the Aging
8 Report does not give an accurate picture of the
9 challenges faced by the ethnically and linguistically
10 diverse group of caregivers in New York City. The
11 Alzheimer's Association is encouraged by a review of
12 DFTA's report, and while New York City has made
13 significant investments to support caregiver
14 services, and is-and is a leader in addressing the
15 burdens caregivers face as reflected in the support-
16 in the report, the City must do more to support its
17 large population of unpaid caregivers especially with
18 information about available services, providing
19 respite care and reaching out to linguistic and
20 ethnic groups that may not be aware of services as
21 well as providing culturally competent services. We
22 look forward to continuing to work with the New York
23 City Council, DFTA and other government and community
24 partners in supporting these invaluable members of

2 our community. Thank you for your time and
3 consideration.

4 CHAIRPERSON CHIN: Thank you. Thank you
5 very much to this panel, and we look forward to
6 continuing to work with you.

7 IAN MAGERKURTH: Thank you.

8 CHAIRPERSON CHIN: We're going to call up
9 the last panel. Anyone else willing--waiting to
10 testify you can also sign up. [pause] Molly
11 Krakowski from JASA and from India House. You have
12 to introduce yourself. I--[pause] Mr. My name is
13 Lakshman Kalasapudi.

14 MOLLY KRAKOWSKI: Hi. My name is Molly
15 Krakowski, Director of Legislative Affairs at JASA.
16 I know we're very late in the day. So, I will keep
17 this short. We are one of the ten providers of
18 caregiver support. So, I just want to get that out
19 there. I'd like to thank Council Member Chin and
20 members of the Aging Committee for today's hearing.
21 I'd also like to thank this committee and the Council
22 leadership and the Administration for the additional
23 \$4 million in the FY18 budget for the Caregiver
24 Program. I'm going to jump ahead and just talk
25 specifically to the Caregiver Program. You know who

2 DFTA—who JASA is, but JASA provides direct assistance
3 to 200 caregivers and reaches nearly a thousand
4 individuals annually helping family caregivers with
5 such services as in-home and group respite care,
6 individual counseling, access to benefits and
7 entitlements, purchase of daily care supplies,
8 installation of home modifications to improve home
9 safety and peer oriented caregiver support—support
10 groups. Through education outreach JASA's Brooklyn
11 Caregiver Respite Program also promotes community
12 awareness about family caregiver—care recipient needs
13 and available resources. We help people avoid
14 crises, and with individual planning for their long-
15 term care needs. JASA's Caregiver Contract with DFTA
16 covers 14 CDs in Brooklyn, and provides funding for
17 three BA level social workers, a program director and
18 a part-time data entry clerk. As we presented in
19 previous hearings, low salaries result in high
20 turnover rates, these workers are not part of that
21 salary parity, just as an aside. JASA subcontracts
22 with homecare agencies to provide up to eight hours
23 per month of respite. The limited number of hours is
24 due to the budget constraints. As of July 1, we pay
25 \$19.50 for—per hour, and this will rise again in

2 January, and there's been no change in the DFTA
3 contract dollars for the past seven years. We
4 anticipate the additional allocation funds for
5 caregiver programs with this new money will help
6 cover the higher cost of providing services, and will
7 result in additional respite hours for clients. You
8 should know that no more than 20% of the caregiver
9 funding can be used for the supplemental expenses
10 such as medical and nutritional supplies,
11 transportation, and other forms of assistance for
12 caregivers. We've had a number of focus groups with
13 caregivers and care recipients to determine areas,
14 which would be supportive. Most caregivers feel
15 socially isolated, and we want to find ways to
16 provide services beyond respite care to give them an
17 opportunity to make them feel as valuable and reduce
18 isolation connecting them with the community. And,
19 while we appreciate DFTA funding for Respite, we also
20 need to invest in new models specifically aimed at
21 reducing the social-social isolation and emotional
22 support. Support for key family caregivers is a
23 vital component of a caring society's commitment to
24 its aging members. It saves public money, deflects
25 unneeded use of hospital emergency rooms, nursing

2 homes and other costly institutions. One year of
3 nursing home placement for one person is reimbursed
4 by Medicaid at approximately \$120,000 in New York
5 State. Consider that in comparison with the entire
6 Brooklyn Caregiver Respite Program of a few hundred
7 thousand dollars, which helps keep hundreds of
8 individuals stable in the community every year.
9 Caregiver programs enable family members to play an
10 active role in caring for their loved ones, and it
11 supports those loved ones in aging and at home with
12 dignity and autonomy, a goal with we all share. We
13 hope that this hearing leads to further discussion of
14 the important issue of support for unpaid caregivers
15 and an openness to proposals to fund proven programs
16 and new initiatives. Thank you.

17 LAKSHAMAN KALASAPUDI: Thank you, Council
18 Member Chin for giving us the opportunity to testify
19 on this important issue, and your tireless leadership
20 for seniors, and [sneezes] excuse me. My name is
21 Lakshman Kalasapudi. I'm the Deputy Director at
22 India Home, and India Home was founded by caregivers.
23 This organization is a product of caregivers taking
24 action not only for their own parents, but realizing
25 that they need to make change in their own community,

2 and so caregiving is very much an important part of
3 why we exist in what we do. As Dr. Corrado mentioned
4 earlier, all of DFTA's services are essentially some
5 kind of service to caregivers. Any senior services
6 that are provided such as our senior centers offer a
7 respite of some kind of emotional wellness for
8 seniors that in turn create a ripple effect for the
9 caregivers and their family. I'm happy to note that
10 many of the people who testified after DFTA such as
11 SNAP, Caring Kind, Alzheimer's Association have noted
12 the need to reach out into ethnic and immigrant
13 communities, and I am saying that we are here. We
14 were founded by immigrants. We are immigrants
15 ourselves, and we know the cultural nuances, and the
16 religious nuances, the dietary nuances of what it
17 means to be a caregiver especially in the South Asian
18 community where there are certain gender norms,
19 certain religious norms. You have to be the most
20 effective caregiver and to most effectively support
21 caregivers, you need to be aware of and sensitive to.
22 One thing in our community is identifying as
23 caregivers is really not prevalent, and so there are
24 thousands and thousands upon—of South Asian
25 caregivers that we know personally who provide care

2 to older adults, but they don't know that they
3 themselves are caregivers, and what resources that
4 they can access. Definitely our partners at SNAP and
5 other larger agencies that have these ten contracts
6 have tried to make in-roads, but-but essentially-
7 essentially the most effective way to target these
8 more linguistically and culturally isolated
9 communities is to do smaller grants for these
10 caregiver program so we can do the outreach in our
11 own languages, and we can most effectively target the
12 multiple different immigrant communities that are in
13 New York City. We are now starting a program from
14 dementia-older adults with mild to moderate dementia,
15 and I'd like to back-piggyback on Jed and the other
16 testimonies that we need more targeted programs and
17 targeted funding for caregivers who provide
18 caregiving for complex-older adults with complex
19 issues such as dementia or even cancer. And one
20 other thing-one other major thing that would be of
21 great use to our community is the Expanded In-home
22 Services for the Elderly Program EISEP, and Bobby
23 mentioned. I-I don't know many South Asians-of the
24 South Asians I know, none of them really know about
25 it. I know there's already an extensive wait list

2 for it, and—and so to think that our community or the
3 people that we serve can even hope to access these
4 services is maybe farfetched unfortunately, but if—if
5 this program is to be expanded that would be greatly,
6 greatly helpful to our communities. Thank you.

7 CHAIRPERSON CHIN: Thank you. I was
8 going to ask you, do you have any clients that EISEP
9 program because we've been fighting to eliminate the
10 wait list. So, there's the more money that's been
11 added. So, I think it's important for you to sort
12 let the community know that they should sign up
13 because if there's a wait list, then we will push for
14 more funding.

15 LAKSHAMAN KALASAPUDI: Okay.

16 CHAIRPERSON CHIN: That's what we've been
17 doing the last couple of years to eliminate the wait
18 list for Medicare.

19 LAKSHAMAN KALASAPUDI: Okay, we will
20 definitely do that.

21 MOLLY KRAKOWSKI: Can I—can I add one
22 more thing?

23 CHAIRPERSON CHIN: Yes.

24 MOLLY KRAKOWSKI: Which is just to say
25 that [coughing] obviously we're very appreciative of

2 the much-much needed money that's going to be coming
3 our way, but as you heard in my testimony, we're
4 currently only able to provide up to eight hours a
5 month of-of respite hours, and you can imagine that
6 even with a flood a money coming in, what we would
7 need to do and what we would like to do in terms of
8 offering current clients additional hours, and I'm
9 sure that the Department for the Aging is expecting
10 that all of these contracts are going to now have
11 many more people who we're going to be serving, which
12 would be understandable, but again, when you're
13 thinking about the number of hours and how that
14 translates out, it will very quickly be not that many
15 hours per client depending on how many people are
16 reached through the campaign. So, it's-it's-it's an-
17 it's an ever-growing number. Obviously, we need more
18 money. We're going to always need more money, but we
19 need more money to serve the current clients. We
20 need more money to serve all the clients that are
21 going to be identified through the outreach efforts.
22 It's-it's not-it's not going to be enough right away.
23 [laughs]

24 CHAIRPERSON CHIN: Well, I agree with
25 you, and that's why we were asking, you know, for

2 some projection of really what the budget needs are,
3 but definitely in your testimony when you just
4 mentioned eight hours a month, that is definitely not
5 enough. I think we could definitely use more, and I
6 know that when we were trying to eliminate the
7 waitlist for the EISEP Program, that one year where
8 they had actually increased hours for existing
9 clients because they were—they were—they had money
10 there that they had to use up. So, we will continue
11 to advocate for those programs, and thank you for—for
12 all the great work that your organization do, and
13 thank you for being here today. Any other
14 individuals want to testify? Okay, if not, the
15 hearing is now adjourned. [gavel]

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C E R T I F I C A T E

World Wide Dictation certifies that the foregoing transcript is a true and accurate record of the proceedings. We further certify that there is no relation to any of the parties to this action by blood or marriage, and that there is interest in the outcome of this matter.



Date December 18, 2017