

CITY COUNCIL
CITY OF NEW YORK

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TRANSCRIPT OF THE MINUTES

Of the

COMMITTEE ON AGING

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December 9, 2014
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HELD AT: 250 Broadway, Committee Room
14th Floor

B E F O R E: Margaret S. Chin
Chairperson

COUNCIL MEMBERS:

Maria Del Carmen Arroyo
Karen Koslowitz
Deborah L. Rose
Chaim M. Deutsch
Mark Treyger
Paul A. Vallone

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

Robin Fenley
Deputy Assistant Commissioner in the Bureau of
Long Term Care and Director of the Alzheimer's
and Caregiver Resource Center at the New York
City Department for the Aging

Kim Hernandez
Assistant Commissioner of Active Aging

Giovana Montalvo-Baer
Director of the Grandparent Resource Center

Reverend Greg Johnson
Emblem Health

Bobbie Sackman
Council of Senior Centers and Services

James Arnold
Executive Council at AARP New York State

Kevin Queen
Vice President at New York Foundation for Senior
Citizens

Erin Brennan
Selfhealth Community Services

Alicia Fry
Services Now for Adult Persons, SNAP

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

Barbara Graves-Poller
MFY Legal Services

Shyvonne Noboa
Sunnyside Community Services

Rimas Jasin
Executive Director of Presbyterian Senior
Services Grandparent Family Apartments

Judy Willig
Heights and Hills

Molly Krakowski
Jewish Association Serving the Aging, JASA

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2 CHAIRPERSON CHIN: Good morning. I'm
3 Council Member Maragret Chin, the Chair of the Aging
4 Committee. I'm pleased to be joined today on the
5 Aging Committee, Council Member Vallone who is now
6 Chair of the Subcommittee on Senior Centers. Other
7 colleagues will be joining us a little bit later.
8 Every day, millions of New Yorkers give unpaid care
9 to family, friends, neighbors and other loved ones
10 unable to care for themselves. These unsung heroes
11 provide everything from 24 hours a day supervision
12 and transportation to housekeeping and personal care.
13 New York's caregivers includes those assisting their
14 parents and grandparents with mental and/or physical
15 disabilities as well as grandparents who care for
16 their grandchildren when the child's parents are not
17 present. Nearly 25 percent of the caregiver
18 population is aged over 75 years old. Caregivers in
19 New York State provide over two billion hours of care
20 monthly, and those served in New York caregiver
21 support programs report an average of 62.6 hours a
22 week of care, 20 hours more than the national
23 average. The voluntary assistance that these
24 individuals provide reduces public spending for long
25 term care support and services with estimates of 25

1 billion in economic value to New York State.

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3 However, the selfless devotion that these individuals
4 give to their loved ones often comes at a high cost
5 for caregivers themselves. Almost two-third report
6 in one survey the need to rearrange their work
7 schedule, decrease their hours, or take unpaid leave
8 to meet their responsibilities. This has resulted in
9 an estimate of three trillion dollars in lost wages,
10 pension and social security benefits nationwide with
11 a fifth of New York's caregiver population reporting
12 annual income of below 20,000. We can see how
13 devastating these losses can be for many families.

14 It is not only the finances, but also the health of
15 the caregiver that's impacted by their overwhelming
16 responsibilities. Employees providing elder care are
17 significantly more likely to report depression,
18 hypertension or pulmonary disease regardless of age,
19 gender and work type. Demands on caregivers
20 associated with greater health risk behaviors,
21 negative stress affecting performance in the
22 workplace and difficulty in taking care of their own
23 preventive health needs. Woman who make up the
24 majority of caregivers in New York encounter
25 particularly hard circumstances including greater

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2 hours of care and a higher level of care than their
3 male counterparts, greater level of stress and more
4 significant, economic losses due to sacrifices in the
5 workplace. Today, we will examine how the city can
6 better provide assistance to caregivers and ease the
7 burdens and challenges they experience on a daily
8 basis. The committee is interested in hearing from
9 the Department of the Aging about the resources they
10 make available to city's caregivers, including the
11 work of the Grandparent Resources Center and the
12 Alzheimer's and Caregiver Resource Center. As the
13 majority of those seniors receiving care suffer from
14 Alzheimer's or related condition, the city must pay
15 particularly close attention to the tremendous
16 responsibilities placed on caregivers who assist
17 these individuals. We are also interested in how
18 DFTA conduct outreach and provide assistance to
19 immigrant and limited English proficiency caregiving
20 families, as language isolation often exacerbates the
21 already significant stresses of caregiving
22 responsibility. It is important that New York City
23 ensure that its supportive services are available to
24 all caregiver population. We look forward to hearing
25 testimony today from DFTA, advocates and those on the

1 front lines of caregiving, the caregivers themselves.
2 The city must demonstrate our gratitude and
3 appreciation for the sacrifices they've made so that
4 another may live a better life. So, I wanted to thank
5 all of you for coming today, and also thank our
6 committee staff, Eric Bernstein [sp?] the Counsel,
7 and James Sabudi [sp?], the Policy Analyst. So,
8 James--I mean, our Eric Bernstein will swear in the
9 first panel.
10

11 COMMITTEE COUNSEL: Can you raise your
12 right hand, please? Do you swear or affirm to tell
13 the truth, the whole truth and nothing but the truth
14 in your testimony before this committee and to
15 respond honestly to Council Member questions?

16 ROBIN FENLEY: There we go. Thank you.
17 Good morning Chairperson Chin and members of the
18 Aging Committee. I'm Doctor Robin Fenley, Deputy
19 Assistant Commissioner in the Bureau of Long Term
20 Care and Director of the Alzheimer's and Caregiver
21 Resource Center at the New York City Department for
22 the Aging, DFTA. I'm joined today by Kim Hernandez,
23 Assistant Commissioner of Active Aging, and Giovana
24 Montalvo-Baer, Director of the Grandparent Resource
25 Center. On behalf of Commissioner Donna Corrado, I'd

1
2 like to thank you for inviting us to testify on the
3 topic of providing support to New York City's
4 Caregivers. Millions of people throughout the US are
5 informal caregivers. More than 65 million
6 individuals provide care for family members who are
7 chronically ill, disabled or aged across the country.
8 These caregivers assist family members by running
9 errands, paying bills, preparing meals, picking up
10 medications, helping with dressing and more. In New
11 York State, there are an estimated 1.9 million
12 caregivers. Approximately 1.5 million individuals
13 serve as informal caregivers in New York City,
14 recognizing that the number could be much longer in
15 that people often do not recognize that they are
16 caregivers. The average time spent in providing care
17 is 21 hours per week, which essentially is a second
18 job for many caregivers. The economic value of these
19 informal caregivers should these services be provided
20 by the formal caregiving system is an estimated 450
21 billion dollars per year. In addition, as of 2011,
22 2.7 million grandparents have served as primary
23 caregiver for their grandchildren. More than half of
24 these grandparents, 55 percent, have been serving as
25 primary caregivers for three years or more and 38

1 percent have been doing so for five years or more.
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3 One-fifth or 22 percent of the grandparent caregivers
4 are living below the federal poverty line, while 10
5 percent among the general population of individuals
6 who are not providing care ages 50 and older are
7 below the federal poverty line. In New York City,
8 about 68,000 grandparents are raising grandchildren
9 under 18 years of age. In 2000, the Older Americans
10 Act was amended for the first time in 25 years in
11 response to the evolving needs of the older adult and
12 the advocacy efforts of their caregiving family. The
13 national family caregiver support program, title 3E
14 of the Older Americans Act, was enacted to provide a
15 full complement of service options to family members
16 or responsible individuals who provide care for
17 adults age 60 and older and to grandparents or old
18 relatives who have primary responsibility for raising
19 grandchildren age 18 and younger. The 2006
20 reauthorization of Title 3E in response to advocacy
21 at the local and national levels has now expanded the
22 definition of those who may be served through this
23 program to include younger grandparents age 55 and
24 older, older adults with disabled children of any
25 age, and families caring for individuals of any age

1 with Alzheimer's Disease or related neurological
2 disorders. The enactment of the National Family
3 Caregivers Support Program represented a significant
4 departure from the historical approach to service
5 delivery under the Older Americans Act. The
6 legislation took an important step toward dismantling
7 the funding silos of the aging, mental health and
8 disabled communities. The program also expanded the
9 target population for aging services by identifying
10 the caregiver who may be under the age of 60 as the
11 primarily recipient of services instead of
12 designating the care receiver as the exclusive
13 service beneficiary. This recognition of the inter-
14 related nature of caregiving made provision of direct
15 services possible for caregivers themselves, such as
16 support groups and trainings on various aspects of
17 care and how to manage their care responsibilities.
18 Critical services and community linkages are offered
19 under the national family caregiver support program
20 to those who are caring for family members at home.
21 The value of addressing the bio psychosocial needs of
22 informal caregivers is well documented. Maintaining
23 the optimum health of the caregiver has been
24 repeatedly demonstrated to delay the
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2 institutionalization of the care receiver and to
3 reduce levels of caregiver and family stress. The
4 importance of supporting caregivers is underscored by
5 the growing cadre of caregivers who are employed,
6 raising their own families, and now find themselves
7 caring for old relatives. Unfamiliar with the kinds
8 of service options available to meet their caregiving
9 needs, these individuals often find themselves
10 confronting competing demands from their job, family
11 obligations and caregiving responsibilities. The
12 intent of the caregiving program is implemented by
13 area agencies on aging, the triple A's of which
14 DFTA's the largest triple A in the US, is to provide
15 one stop shopping so that the needs of caregivers can
16 be assessed and addressed through information,
17 education and service linkages for themselves and
18 their care receivers. There are five service
19 categories authorized under the caregiver program,
20 information about services, assistance with accessing
21 services, individual counseling, support groups and
22 training, respite care and supplemental services.
23 Respite care involves services such as congregate
24 care for the care recipient, in-home care, and
25 institutional overnight stays. In order to be

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2 eligible for respite care, the care receiver must be
3 impaired in at least two activities of daily living,
4 or ADL's. That is he or she must need physical
5 assisting, verbal cueing or extensive supervision in
6 order to bathe, dress, eat, ambulate or toilet.

7 Under supplemental services which are designed to
8 provide nontraditional assistance, the require for
9 two ADL's also applies. Examples of supplemental
10 services can include purchase of incontinence
11 supplies, medications, minor home modifications and
12 transportation. Caregiver clients are empowered to
13 identify their care needs while working with their
14 case manager who acts as a liaison to the provider of
15 service. The ADL stipulations, however, do not apply
16 to the grandparent seeking respite or supplemental
17 services for their grandchild. Respite and
18 supplemental services in this instance can include
19 summer sleep away camp and tutoring services,
20 respectively. It is important to note that funding
21 for respite and supplemental services is limited with
22 the judicial expenditure of these funds incumbent
23 upon each caregiver program. DFTA has contracted
24 with community based organizations, CBO's, citywide
25 since 2001 to provider services under the National

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2 Family Caregiver Support Program. Currently funded
3 at four million for fiscal year '15, DFTA's ten
4 caregiver programs have served approximately 9,000
5 individuals throughout the city since July of this
6 year, providing information about caregiving,
7 discussing the associated stressors and offering
8 pertinent resources. Other caregivers have received
9 counseling and have participated in support groups
10 and trainings through these programs. Seven of the
11 10 DFTA sponsored caregiver programs serve designated
12 catchment areas. Of these seven programs, three
13 serve grandparents raising grandchildren in addition
14 to working with adult, child, and spousal caregivers.
15 We also have programs that assist caregivers
16 citywide. One program serves Chinese, Japanese and
17 Korean caregivers. Another program serves the blind
18 and visually impaired, and a third program serves the
19 LGBT caregiving community. In terms of language
20 access, caregiver services are provided to
21 individuals who speak Spanish, Russian, Polish,
22 Ukrainian, Pilipino, Greek, Mandarin, Cantonese,
23 Korean, and Japanese. Language line is available for
24 other languages or dialects. All programs provide
25 ongoing community educational forums on topics

1 related to caregiving and the many aspects of long
2 term care. Collaborative caregiver public forums
3 have been successful outreach opportunities in
4 addition to the provision of information. It's
5 important to note that included among the caregivers
6 served are long distance caregivers who live out of
7 state or out of the country. The working caregiver
8 and more recently young caregivers. That is children
9 who've become caregivers for their grandparents or
10 other relatives. Each type of caregiver has their
11 own unique concerns and situations with the
12 commonality of providing care for a loved one
13 crossing all caregivers, working to allow the care
14 receiver to remain at home and in their community for
15 as long as possible. DFTA's also a member of a
16 number of caregiver coalitions. The state appointed
17 DFTA as a member of the New York State Family
18 Caregiver Council in 2007, which conducted the first
19 New York State Caregiver Survey on the impact of
20 these caregiver services. DFTA is involved in the
21 New York State Office for the Aging's Caregiver
22 Coordinators Group and has presented in numerous
23 venues and areas of the state on issues facing the
24 diversity of New York City caregivers. Additionally,
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1 Emblem Health launched the New York City Family
2 Caregiver Coalition in 2006, which now resides with
3 the Council of Senior Centers and Services. DFTA
4 participated in the early development of this
5 coalition and remains a member today. In January
6 2015, Commissioner Corrado will co-chair a meeting
7 hosted by the New York City Partnership for Family
8 Caregiving Corps, which will welcome a number of
9 corporations partnering in the creation of responsive
10 guidelines for corporations that are increasingly
11 encountering the working caregiver. You'll hear more
12 about this partnership today from Reverend Greg
13 Johnson who will testify on behalf of Emblem Health.
14 Year ago, DFTA recognized that an increasing number
15 of the city's older adults were caring for their
16 children, their grandchildren or other young
17 relatives and responded with programs to support
18 them. The Grandparent Resource Center, GRC, the
19 first of its kind in the nation was established by
20 DFTA in 1994. The GRC provides a number of
21 supportive services to those older adults who are
22 raising grandchildren and other young relatives.
23 Resource specialists at the GRC offer advocacy and
24 case assistance, as well as referrals to appropriate
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2 community based organizations. These community based
3 organizations provide services such as preventive
4 services, legal services, financial assistance,
5 advocacy, educational services, tutoring services for
6 children, family counseling and support groups. In
7 addition, the GRC holds workshops on topics such as
8 financial entitlements, mental health and wellness,
9 grandparent empowerment, kinship foster care,
10 adoption and child custody options as well as
11 navigating the city's child welfare system. The GRC
12 also sponsors a resource library, holiday toy drive
13 and recreational activities for grandparents and
14 their grandchildren. Finally, the GRC facilitates
15 and provides information about community support
16 groups for grandparents raising grandchildren. In
17 fact, the GRC sponsors a network for grandparent
18 support group facilitators which cultivates the
19 exchange of ideas, event collaboration and
20 specialized training. The GRC has worked to provide
21 information and referrals, case assistance and
22 trainings. Working with community partners, the GRC
23 organizes educational forums and events for the
24 grandparent caregiving community. GRC presentations
25 and trainings for caregivers are held at local

1 schools, hospitals, churches, and other religious
2 institutions. From 2013 to 2014 there were 677 new
3 grandparent caregivers served and 541 participants in
4 GRC sponsored support groups held in different
5 neighborhoods in the city. Through the GRC 764
6 grandparent caregivers received information during
7 that period. DFTA's made efforts to create a one-
8 stop point of reference for kinship care providers
9 through the GRC. For kinship caregivers who prefer
10 using a resource manual, DFTA provides resource
11 guides that outline benefits and services available
12 to kinship caregivers and how to access these
13 services. The resource guide and support group guide
14 for grandparents raising grandchildren are available
15 on the DFTA website and are distributed at outreach
16 events and through DFTA's network of aging services
17 providers. In order to serve some of the neediest
18 kinship caregiving families, GRC programming has most
19 recently expanded in July of this year under the
20 Mayor's New York City Housing Authority anti-violence
21 program. The GRC received 472,000 in fiscal year '15
22 for DFTA community advocates to work with residents
23 at 15 NYCHA developments and provide resources and
24 services to grandparent caregivers. Through this
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2 initiative grandparent caregivers will receive
3 grandparent education, trainings and peer support on
4 raising grandchildren. In conclusion, thank you for
5 this opportunity to provide testimony on supporting
6 New York City's caregivers. We're glad to answer any
7 questions you may now have.

8 CHAIRPERSON CHIN: Thank you. We're also
9 joined by Council Member Deutsch from Brooklyn.
10 Council Member Vallone, you have questions? I can
11 let you go first.

12 COUNCIL MEMBER VALLONE: That's like an
13 early Christmas present. Good morning.

14 ROBIN FENLEY: Good morning.

15 COUNCIL MEMBER VALLONE: How's everyone?
16 This is a wonderful way to start reviewing what has
17 been done and we thank you for the testimony. So
18 many great things you mentioned. I think for me
19 being on for the first year and learning all the
20 different things it's exciting. There's a lot of
21 limitations here, and I see a lot of it stemmed from,
22 in looking at your testimony, from changes in the
23 federal guidelines. Could you kind of briefly go
24 back and how did DFTA changes as the changes occurred
25 back in 2007, 2010 on the federal level? What

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2 specifically did DFTA do differently as the changes
3 happened on the federal level?

4 ROBIN FENLEY: Well, certainly it comes
5 to the RFP process and depending on where we were in
6 the RFP process. The funding allowed us to even
7 rethink about communities that were being served and
8 what communities weren't. So, specifically, and I
9 believe it was about the 2006, 2007, which is where
10 we began to look at citywide programs, caregiver
11 programs for the underserved communities, and that's
12 really where we began learning, frankly, from our on
13 pre-existing providers about grandparents who were
14 raising grandchildren so that we could target that
15 community as well as the LGBT community and the non-
16 English speaking communities. So in terms of
17 programming around the caregiver program, those
18 federal dollars absolutely allowed that sort of
19 broadening of vision and awareness, even within the
20 Department.

21 COUNCIL MEMBER VALLONE: Do we know how
22 many of those federal dollars? So the granting
23 process is actually coming to New York?

24 ROBIN FENLEY: Yeah, all four million is
25 New York and it all goes out, the four million that

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2 we get from the feds through the state goes out to
3 our programs.

4 COUNCIL MEMBER VALLONE: Do we have a
5 breakdown? I mean, I see there's a four million
6 dollar budget that you have. I mean, supplement to
7 that, do we have an idea of how much funding in total
8 is now going into caregiver projects?

9 ROBIN FENLEY: Oh, across the country?

10 COUNCIL MEMBER VALLONE: No, here in New
11 York.

12 ROBIN FENLEY: It is the four million
13 dollars, again coming out of the title 3E. I mean,
14 if you wanted a breakdown in terms of, you know, how
15 much per borough per contracted program, we certainly
16 could get you that, but all of that four million that
17 we're getting is going right out to the community.

18 COUNCIL MEMBER VALLONE: Well, I mean, I
19 didn't want to the jump to the four million first,
20 but I am seeing how the city uses our budgetary; four
21 million is clearly not enough. So, what I'd like to
22 see is an all-out effort, because in every hearing
23 that our Madam Chair has held and through the
24 Council, the aging population is number one in the
25 city. Aging issues is number one in the city.

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2 There's not a hearing that we have in the city that
3 doesn't involve aging issues, and now related to that
4 with today's topic with caregivers, whether it's
5 grandparent, parents, or children that are now--
6 there's three generations that are providing support,
7 and I think the confusion when we hear from the
8 groups and everyone is where that centralization all
9 for everyone. So whether it's a grandparent, whether
10 it's a parent, whether it's a child, when we need to
11 care for a person in need, what is the first step?
12 What is DFTA's role? And I think that uniform
13 process on streamlining it, is there an effort now to
14 maybe do that, to kind of loop them all together in
15 this caregiver world?

16 ROBIN FENLEY: Oh, absolutely,
17 absolutely. DFTA functions as the conduit. So,
18 wherever request for assistance come, we will do the
19 assessment, and whether it involves the GRC or any of
20 our other units within the Department, they are
21 immediately brought in on the situation and then the
22 referral is given then to our appropriate provider in
23 the community. So it becomes--it really is community
24 effort, not only within DFTA, but also with our

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2 community partners in providing care whoever or
3 services to whoever it is that's in need.

4 COUNCIL MEMBER VALLONE: Well, I may
5 suggest--I think, almost 25 years I served and did
6 kinship hearings and guardianship hearings in the
7 courts, and not once in any proceeding did the judge,
8 did paralegal, did APS, did DFTA come and have any
9 type of resources available for the AIP, the Alleged
10 Incapacitated Person. I saw these resource guides
11 that you mentioned and providing GRC knowledge and
12 outreach, it was never mentioned. So, I think maybe
13 we can expand a partnership within the legal
14 community whose fighting this onslaught of cases that
15 are happening as to the judicial, the illegal--as to
16 the services that DFTA does provide and maybe for
17 input from the community as to what the current
18 demand is. Do you have anything that work in
19 coordination that's happening now within the actual
20 legal proceedings that deal with the kinship and
21 guardianship, do you have any of that information?

22 ROBIN FENLEY: I would defer to Giovana
23 or Kim [sic].

24 COUNCIL MEMBER VALLONE: Just turn that
25 mic on, thanks. And identify so we know.

1
2 GIOVANA MONTAVLO-BAER: Hi, my name is
3 Giovana--

4 COUNCIL MEMBER VALLONE: [interposing] I
5 don't think it's on yet. You see the red light come
6 on yet? There should be a button the black-

7 GIOVANA MONTAVLO-BAER: Is that good?

8 COUNCIL MEMBER VALLONE: There you go.

9 GIOVANA MONTAVLO-BAER: Hi, Giovana
10 Montalvo-Baer, Director of the Grandparent Resource
11 Center. We do work with people within the community
12 who provide services, legal services for kinship care
13 and mores specifically we work with MFY [sic] Legal
14 Services. They have a kinship program, and as I
15 needed, I'm also on the Elder Abuse Subcommittee for
16 in the Bronx to assist grandparents who have issues
17 within the legal system for grandparent caregivers,
18 and we do go out to community, let people know about
19 our services and impact different people from, you
20 know, who are involved with the child welfare
21 service, if they've come to our PASA program which is
22 called Parenting the Second Time Around in lieu of
23 going to a parenting skills program at a ACS funded
24 program. They go to our PASA program which is more
25 of a grandparenting/parenting skills program.

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2 COUNCIL MEMBER VALLONE: Well, how do
3 they find out about that?

4 GIOVANA MONTAVLO-BAER: By advertisement.
5 We market. Again, we go to the schools. We go to
6 the local community board, community--

7 COUNCIL MEMBER VALLONE: [interposing]
8 Well, we want to help you. I mean, we want to help
9 spread the word on it. So I'm just saying so maybe
10 this is an opportunity. What we could we--what do
11 you see in working with these programs that's the
12 increase demand that you'd like to tackle next?

13 GIOVANA MONTAVLO-BAER: Increased demand,
14 definitely want--I would love for me people to know
15 about the, you know, the different resources we have,
16 because it's still something that people still are
17 not aware of the services specifically for
18 grandparent caregivers. Again, a lot of times this
19 self-identification. They don't realize that there
20 is a program out there for somebody that is raising
21 their grandchild, because they believe this is part
22 of the family, I should be doing this, and not
23 realizing that there's other services out there. But
24 when we go out to the community to let them know that
25 there's a grandparent resource center, or if you're

1
2 at odds raising a nephew or a niece, that you could
3 still benefit from the services of the Grandparent
4 Resource Center. So, I guess it's just awareness.
5 One is self-identification, and then the other one is
6 just know of the resources there is out there.

7 COUNCIL MEMBER VALLONE: Well, I would--I
8 may suggest before you jump in. I think that
9 conversation with the legal community would be
10 critical because the services are exactly what
11 they're looking for at that point, at that hearing,
12 where could we turn as family to get assistance as
13 they're facing these proceedings. They don't know
14 where to go. So, I think that might be an area.

15 KIM HERNANDEZ: Council Member, I'd also
16 like to add to that we do have a DFTA website where
17 all of our information is available.

18 COUNCIL MEMBER VALLONE: Can you just
19 identify, so we know who's testifying.

20 KIM HERNANDEZ: Oh, my name is Kim
21 Hernandez.

22 COUNCIL MEMBER VALLONE: Thank you.

23 KIM HERNANDEZ: And I'm the Assistant
24 Commissioner for the Bureau of Active Aging and
25 Grandparent Resource Center falls under my bureau.

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2 So, we do have our DFTA website, and additionally, we
3 do receive numerous calls directly through 311
4 because we have a warm line from 9:00 to 5:00 each
5 day, and so we're able to talk to people who are in
6 need. Additionally, our services are in different
7 languages as well, primarily in Spanish and in
8 Russian through our community coordinators who work
9 in our unit.

10 COUNCIL MEMBER VALLONE: So the 311 call
11 goes into the DFTA case management system?

12 KIM HERNANDEZ: Yes, it's a live call.
13 So, it comes directly through, and you know, if it's
14 after work hours then we'll call the person
15 immediately the next business day. Additionally,
16 another thing that we really always want to do and
17 love to do is to do presentations for the Council
18 Members about our programs, particularly for your
19 line staff so that they're aware and we can--and they
20 can contact us when they have people that are coming
21 into your offices that need this type of assistance.
22 And so we're able to do those presentations. We've
23 also found that through numerous other programs
24 through DFTA, using the resources of your newsletters
25 is really very good, because it gets out to people in

1
2 your district, and then they're able to contact us as
3 well.

4 COUNCIL MEMBER VALLONE: And just to kind
5 of--you mentioned the community based organizations
6 and the contracts DFTA has. Could you expand on how
7 many we have, when the last time the contract or the
8 RFP's went out, and is that system working?

9 ROBIN FENLEY: It's absolutely working.
10 The last, this current group has been--oh, boy.
11 Let's see. We're three years, so it's about six
12 years ago they've now been with us. So, six years
13 ago we had--this group we've had. It will be up for
14 solicitation in the near future. It does work,
15 although, you know, as we're saying it's always about
16 the dollars, and the dollars shape the number of
17 programs that we're able to fund. But it's--

18 COUNCIL MEMBER VALLONE: [interposing]
19 And that's within the four million?

20 ROBIN FENLEY: Sorry?

21 COUNCIL MEMBER VALLONE: That's also
22 within the four million?

23 ROBIN FENLEY: Yes, yeah, yeah.

24 COUNCIL MEMBER VALLONE: We're going to
25 have to take a look at that. I can't see--

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ROBIN FENLEY: [interposing] Excellent.

COUNCIL MEMBER VALLONE: how we can do all of these wonderful things we're talking about with four million dollars.

ROBIN FENLEY: Well, you know what, it's a very committed group of providers. They are able to do--

COUNCIL MEMBER VALLONE: [interposing] Oh, I know.

ROBIN FENLEY: miracles on shoe strings, but yes, if there is more dollars that's always, always welcomed.

COUNCIL MEMBER VALLONE: Do you have the breakdown per throughout the city and then per county on the community based? Like, how many organizations are assisting throughout the different counties and throughout the city?

ROBIN FENLEY: In terms of the caregiver program? Sure, yeah. We have one on Staten Island. We have two in Brooklyn, two in Queens. We have two that cover the Bronx, and in Manhattan we have one that covers the upper part of Manhattan, and we have three that serve citywide that are located in Manhattan.

1
2 COUNCIL MEMBER VALLONE: And they've been
3 consistent for the last six years? There hasn't been
4 any changes?

5 ROBIN FENLEY: Yes, yeah, that's correct.

6 COUNCIL MEMBER VALLONE: Any amendments
7 or policy guidelines that they've had to adapt to or
8 change to over the time, or?

9 ROBIN FENLEY: Well, there have been in
10 terms of, you know, just more in terms of the bean
11 counting that comes from the state in terms of how
12 certain services are counted, but the service is
13 still being delivered, you know, as originally
14 intended.

15 COUNCIL MEMBER VALLONE: Do you have the
16 data on the amount of clients that they've served or
17 that have the demand as increased over the last six
18 years?

19 ROBIN FENLEY: I would be able to get you
20 that.

21 COUNCIL MEMBER VALLONE: That might be
22 helpful as we fight for the dollars.

23 ROBIN FENLEY: Sure, sure. You know, in
24 the testimony I think I'm saying that the programs had
25 served nine, provided about 9,000 caregivers

1
2 individuals information since July. So the numbers
3 can be pretty substantial, but sure, I'll get you
4 that.

5 COUNCIL MEMBER VALLONE: And then my last
6 question is you said something that was very telling.
7 Seventy-five percent of all of these cases are based
8 on Alzheimer's with dementia. So, I--is there a
9 focus now based upon that staggering number as to
10 services that are going to be provided for as the
11 aging generation continues and dementia continually
12 becomes this cloud on how you define it, how you
13 care, when it triggers the ADL's and when a
14 psychiatrist and psychologist--just it's a never
15 ending quagmire of how you determine dementia. What
16 is APS's vision for dealing with that increased
17 number of dementia cases and Alzheimer's?

18 ROBIN FENLEY: Well, DFTA's vision, I
19 can't answer for APS, but DFTA's vision for it is
20 just to be able to continue. Well, we collaborate.
21 Our collaborations are certainly with the Alzheimer's
22 Association, with all providers. We also do
23 collaboration even with the researchers. Some of the
24 researchers are interested in, for instance Doctor
25 Mary Middlman [sp?] at NYU has done landmark study on

1
2 providing services for caregivers of individuals
3 caring for people with dementia. Showing the
4 supports that are provided keep the people out of the
5 nursing home about a year on average, two years
6 almost. Taking that--

7 COUNCIL MEMBER VALLONE: [interposing]

8 Is there any specific programming?

9 ROBIN FENLEY: Sorry?

10 COUNCIL MEMBER VALLONE: Is there any
11 specific program within DFTA that deals with this or
12 it's a collaboration of just--

13 ROBIN FENLEY: [interposing] Oh, no, it's
14 a collaboration that we're doing.

15 COUNCIL MEMBER VALLONE: APS?

16 ROBIN FENLEY: Which it's all
17 collaboration that we do. It's with our caregiver
18 programs, and the services that are provided through
19 the caregiver program, they're the same quite
20 honestly whether you're caring for somebody with a
21 dementia or somebody with a stroke, or with some
22 other chronic illness. It's more intense. It's the
23 intensity of it. it's the number of hours that are
24 needed. And this is where it really does get
25 challenging for the caregiver of somebody with

1
2 dementia, because there's so many hours of intense
3 supervision that's needed, not even so much the
4 nursing care, it's just the monitoring. And that's
5 where we run into problems. So it's really just a
6 more intense provision of the care.

7 COUNCIL MEMBER VALLONE: Well, I'd love
8 to be able to see going forward. These are where I
9 think the caregivers are overwhelmed in these
10 instances, because it's a 24 hour, seven day a week.

11 ROBIN FENLEY: Right.

12 COUNCIL MEMBER VALLONE: And there's not
13 enough relief at all provided for the caregivers on
14 the three different generations, from grandparents,
15 parents and children now, you know, that have to step
16 up. So, I think this is clearly not adequate.

17 ROBIN FENLEY: Yeah.

18 COUNCIL MEMBER VALLONE: On the four
19 million on dealing. So you'll have to see the
20 increase in the fight in this year's budget so we can
21 fight with you to make that a reality.

22 ROBIN FENLEY: Thank you.

23 COUNCIL MEMBER VALLONE: Thank you very
24 much.

1
2 CHAIRPERSON CHIN: Thank you. Council
3 Member Deutsch, you had a question?

4 COUNCIL MEMBER DEUTSCH: Yeah, thank you,
5 Madam Chair. I have--I fund an organization in my
6 district that deals with entitlement issues. I have
7 for example, a few thousand at least constituents
8 that are eligible for the SNAP program that are not
9 enlisted in the SNAP program. So, we try to do as
10 much outreach as possible, let people know that
11 they're eligible for these city services, city and
12 state services. So, when people call my office we go
13 through and we have the one on one. We have a social
14 worker who goes with them one on one basis to go
15 through their finances to see if what city services
16 they may be eligible to. So, number one, I'd like to
17 ask Ms. Hernandez if we can do like a forum in my
18 district on the caregivers program? Because many of
19 my seniors don't have access to computers, and they
20 know to call 311 when there's a pothole, but not for
21 this program. So, I would love to have something,
22 like a district wide forum, not a town hall meeting.
23 No one's going to be shouting at you, but just to
24 give them information on who might, who may be
25 eligible for the caregivers program. Because I see

1
2 many families are struggling each and every day who
3 may be entitled to a such program, and they just
4 don't know about it.

5 KIM HERNANDEZ: Council Member, we would
6 be delighted to do that, and I think that would
7 really be, you know, both of our bureaus, Long Term
8 Care and Active Aging and perhaps other resources,
9 because that is important. That one on one contact
10 with the client is extremely important and the person
11 in the district, and we would be happy to do that.

12 COUNCIL MEMBER DEUTSCH: Great, I
13 appreciate it. I look forward to having this forum.
14 Thank you.

15 CHAIRPERSON CHIN: Thank you. So, right
16 now, how many staff do you have currently, staffing
17 with the Alzheimer and the Caregiver Resource Center
18 and also the Grandparent Resource Center?

19 ROBIN FENLEY: In the Alzheimer's unit we
20 have three full time social workers and two part time
21 social workers. In the GRC?

22 GIOVANA MONTAVLO-BAER: Okay, in the GRC
23 we currently have three community associates, and at
24 the same time we're in the midst of hiring three
25 community advocates for the MAP [sic] program.

1
2 Excuse me, that's a NYCHA Anti-Violence Program. So
3 they're in the process of being hired.

4 CHAIRPERSON CHIN: So you already have
5 three community associates? What does that mean?
6 They just go out and do workshops, or?

7 GIOVANA MONTAVLO-BAER: Community
8 Associates, it's a combination of answering the phone
9 calls, going out into the community, doing
10 presentations, sitting on different meetings, and
11 basically whatever needs to be done gets done.
12 They're the advocates behind the grandparents. They
13 go to HRA as necessary. They go to the schools and
14 do presentations if necessary. They answer phone
15 calls and answer questions that's necessary.

16 CHAIRPERSON CHIN: So, are they the one--
17 so you're saying they're the ones that actually
18 advocate for the grandparent?

19 GIOVANA MONTAVLO-BAER: That's correct.
20 They advocate depending on the situation. Sometimes
21 they're resources for the grandparents if they just
22 need a combination of hand holding or they need
23 somebody to be there at, you know, at an educational
24 meeting or for the advocates to advocate for them on
25

1
2 their behalf, or to go to HRA if they need those
3 services.

4 CHAIRPERSON CHIN: So what is the CBO
5 that DFTA contract with, what do they do then? I
6 mean, I would assume that you would refer or connect
7 this grandparent with a CBO that can work with them
8 on a long term basis.

9 GIOVANA MONTAVLO-BAER: No, I--they--if
10 it's for short term services that we do the--we do
11 the services at the Grandparent Resource Center. If
12 they need additional services or something that's a
13 little bit more complex, we do refer out to the
14 community.

15 CHAIRPERSON CHIN: So what is an example
16 of a short term that you can just resolve for them?

17 GIOVANA MONTAVLO-BAER: I was going to
18 say a phone call, if they just need information, or
19 let's just say they're having problems with the
20 child at the school, we go for them. Or let's just
21 say they're having problems with--let's just say
22 their HRA services and they need additional services
23 for that. One of the things that we currently work
24 on, one of the things we have is a presentation for
25 HRA services, letting the know that you could get the

1
2 public assistance on behalf of the child. However,
3 sometimes they go to HRA, you know, they're often
4 told that--or they have been told in the past that
5 they are not eligible for the services because they
6 don't have custody or guardianship and we often
7 advocate on their behalf that this is something that
8 they're eligible for in spite of not having legal
9 documentation, information like that.

10 CHAIRPERSON CHIN: Also, in previously
11 the Mayor's management report, the Department of
12 Aging separate the number of caregiver who receive
13 service from DFTA from those receiving service from
14 the contracted provider. What's the logic behind
15 that? You have these two separate populations?

16 ROBIN FENLEY: That's a good question,
17 you know, but I do not know the answer to that. We
18 can find the answer for that.

19 CHAIRPERSON CHIN: You had it separately
20 before, now you just lumped it all together.

21 ROBIN FENLEY: Right, you know, I know
22 within the Department we've been doing different--
23 looking at how the data can be presented in a most
24 cogent way, and so I'm not sure frankly what was
25 behind separating it out from in-house and contractor

1
2 providers or putting them together. That I can find
3 out, and I would be glad to get back to you on that.

4 CHAIRPERSON CHIN: Okay, and also--I
5 mean, you talked about the group that provides
6 citywide services are the one that can provide all
7 these different languages.

8 ROBIN FENLEY: Not all of that. We have
9 actually a lot of those languages came from Brooklyn,
10 one of Brooklyn providers and also Spanish is many of
11 the programs, but the unique languages, if you will,
12 was Queens and Brooklyn in addition to our citywide
13 in Manhattan.

14 CHAIRPERSON CHIN: But what kind of
15 services I guess these--the CPO's provide?

16 ROBIN FENLEY: They all provide the same
17 five set of services, the information, accessing of
18 the--assistance accessing benefits, support groups,
19 trainings, respite and supplemental services. So, in
20 terms of providing that sort of information to the
21 caregiver, those are provided in those specific
22 languages, and the good thing about having the
23 providers who have this language ability is that they
24 also know what provider--so, say homecare would be
25 able to speak the same language of the care receiver.

1
2 So, I mean, that can make a world of difference in
3 the home. So, that's the benefit of that.

4 CHAIRPERSON CHIN: I think come down to
5 it is really how do we get the information out into
6 the community so that people know that the resources
7 are available?

8 ROBIN FENLEY: Right.

9 CHAIRPERSON CHIN: With the four million
10 dollars, you don't have money to even advertise on
11 the bus stop or a subway.

12 ROBIN FENLEY: Funny you should say that
13 because years--when this program first started we did
14 have money to do that, and we had a campaign that was
15 in the subways on and on the bus shelters and in the
16 buses for several months, but that was it. That was
17 sort of the one shot deal. And then it becomes word
18 of mouth, and as you know, in many of the immigrant
19 communities it is word of mouth, but it is about
20 doing that outreach, and so like the GRC, Alzheimer's
21 and the caregiver programs are always out in the
22 community at health fairs and collaborative events
23 with other local providers offering forums or
24 seminars on the various topics to raise that
25 awareness that they are providing care, that they are

1
2 caregivers and that there are resources available.

3 So it is, it is absolutely a challenge to be able to
4 get that out there.

5 CHAIRPERSON CHIN: So, I mean, to go back
6 to what Council Member Vallone raised about the four
7 million dollars in the FY 15 budget, and you said all
8 of that money is coming from the federal government.

9 ROBIN FENLEY: Yes, it goes through the
10 state, but it's from the feds. The entire thing,
11 quite frankly, started out that the feds funded
12 across the country in 2000 at 125 million. Over the
13 years, it's gotten to maybe 165 million. So it's not
14 much that's even coming from the federal level, and
15 that's got to go to all of the triple A's across the
16 country, because this program is provided by all the
17 triple A's throughout the United States.

18 CHAIRPERSON CHIN: So you're not getting
19 any support from the state either, huh?

20 ROBIN FENLEY: Well, no, the state, you
21 know, they hear it. They understand, and I think
22 everybody within the confines and limitations of what
23 they can do, do. You know, everybody knows and is
24 increasingly aware of the importance of caregiving,
25 caregivers and getting the information out.

1
2 CHAIRPERSON CHIN: Because all the
3 statistic that we talked about in your testimony and
4 my opening remark, I mean, this is a tremendous--

5 ROBIN FENLEY: [interposing] It's huge.

6 CHAIRPERSON CHIN: issue. I mean, like,
7 somehow we have to really get the resources and get
8 the word out.

9 ROBIN FENLEY: Right.

10 CHAIRPERSON CHIN: Because four million
11 dollars, I mean, there's no match from the state and
12 there's no match from the city. I mean, City
13 Council, we give discretionary money to organizations
14 in the community that provide the support services.

15 ROBIN FENLEY: And they appreciate that.
16 You know, so every now and again we see these
17 amendments that come through, and it's very much
18 appreciated and put right out to the caregivers.

19 CHAIRPERSON CHIN: Yeah, I think we
20 really have to strategize how we can work together
21 with the advocates to really--

22 ROBIN FENLEY: [interposing] Great.

23 CHAIRPERSON CHIN: bring more resources
24 to this. I have a couple of questions from Council
25 Member Rose who couldn't be here today. She wanted

1
2 to know if all the number and the demographic of the
3 informal caregiver in New York State as well as the
4 hours they provide, is there a way to break it down
5 locally by council district?

6 ROBIN FENLEY: I suppose we could give it
7 a try.

8 CHAIRPERSON CHIN: Yeah.

9 ROBIN FENLEY: What I would say is that
10 what I have seen are the national studies are
11 mirrored in New York City data. So, it's kind of
12 backing into it. Because again, a lot of this as I
13 was saying in the testimony, a lot of the caregivers,
14 you know, we can estimate that there's a couple
15 million roughly, but it's a guesstimate, because
16 people don't identify, as Giovana was saying, that
17 what they are doing is providing care. So, what the
18 real number is and how many hours they really put in,
19 it is a guesstimate, and so the best that we could do
20 is to back into it from the national studies. We can
21 give that a try.

22 CHAIRPERSON CHIN: Yeah, because that
23 also would help each Council Member to see how big an
24 issue it is to their community. And also, she wants
25 to know what exactly is being done to ensure that

1
2 culturally competent outreach happen in all areas of
3 the city so that the caregivers knows about the
4 resource and the system support that are available?

5 ROBIN FENLEY: Well, again, you know,
6 certainly having the providers who are able to hire
7 staff from the--who are culturally and linguistically
8 competent, that's totally the key. Not everybody is
9 able to do that. Within the Department we actually
10 had started Chinese-American Alzheimer's Coalition,
11 and we're helping to develop a Korean-American
12 Alzheimer's Coalition. And so events like that will--
13 -coalitions such as that will have events in their
14 communities in the languages and get the word out
15 that way. That's been very effective. But once
16 again, it comes down to collaborating with other
17 partners who do have that skill set and individuals
18 who speak those languages to help get the word out.
19 That is--and in New York City, as diverse as it is,
20 it is a challenge, yes.

21 CHAIRPERSON CHIN: Yeah. And the last
22 question she had was, what is being done to address
23 the potential future shortage of caregivers? I mean,
24 what step can we do now to get ahead of this,
25 particularly how dependent we currently are on

1
2 informal caregivers to cover the gaps for our
3 children and for our elder care.

4 ROBIN FENLEY: That is an excellent
5 question, and that's one that begs an answer I think
6 on a policy level as well as on a family level and a
7 community level. This is really the village idea,
8 because there are not going to be enough family
9 members to provide that care. There's not going to
10 be enough services actually like institutions, if you
11 will, to provide the kind of care that's needed. So,
12 it is a serious issue.

13 CHAIRPERSON CHIN: So, working, I mean,
14 obviously you're working with the providers that you
15 have funded. What have you heard? I mean, what is
16 the most crucial support that these caregivers need
17 or things that we should be focusing on?

18 ROBIN FENLEY: Well, in terms of the data,
19 it shows that everybody needs information. So it
20 kind of goes back to the outreach to be able to give
21 people information about the services, but in terms
22 of the actual service, mostly it's respite. People
23 need a break. Caregivers need a break, and whether
24 we're talking in-home services--well, actually,
25 that's usually what people are preferring is the in-

1 home homecare worker. That's really number one.

2 Transportation is an issue. Mental health, as people
3 are beginning to acknowledge the reality of mental
4 health and depression, people are beginning to look
5 at that and wondering how to access that. So, do we
6 have enough services for that available in the city?
7 Right, but it's mostly respite services at this
8 point.
9

10 CHAIRPERSON CHIN: What about the social
11 adult daycare? I mean, in terms of really focusing
12 on supporting the real social adult daycare, not the
13 one that's popping up all over the city. So, I mean,
14 we want to get a handle on that, but we also have
15 really good social adult daycare programs that some
16 of them are not getting referrals, you know, from the
17 long term care agencies, and they're the one that can
18 provide the respite. Well, that, frankly, when you
19 talk about referrals, that's one of the things, and
20 again, it supports what Giovana was talking in terms
21 of the work of the GRC. I think all of the units
22 within the Department, certainly that are dealing
23 between case management and caregiving and GRC, is
24 that we internally and certainly our contracted
25 providers know about this service, and so when we

1
2 have our meetings, we are reminding each other about
3 each other's services, because the three of them
4 really can partner beautifully and put a nice package
5 together of services, if you will, for the caregiving
6 family. So, it is about that, and I just hope, you
7 know, we are meeting routinely and reminding each
8 other about the services that are out there. And
9 it's great because our providers in the community
10 also tell us about the services that they've come
11 across in the community that we might not be aware
12 of. So it's a great information network, I think,
13 that's being developed around caregiving.

14 CHAIRPERSON CHIN: One more question.
15 The NYCHA, the project at NYCHA, has that started?
16 Is there any results?

17 GIOVANA MONTAVLO-BAER: The project has
18 started right now where it's, as I mentioned before,
19 we're still in the middle of getting the--getting
20 three community advocates. I, myself, and other
21 people from the GRC staff, we've gone out to the
22 community and met with different individuals who work
23 in the NYCHA facilities, such as the Tenant
24 Association, primarily the Tenant Association
25 presidents, the people who work at the DYCD

1
2 Cornerstone's facility which is where the community
3 advocates are going to be housed or the people within
4 the senior centers within the NYCHA facilities. So,
5 it has started on some basis. Right now, we do have
6 a support group that is ongoing at one of the 15
7 developments, but once we get the people they're just
8 going to get started, and I think, I believe that
9 would happen by the end of the year. They should
10 come on board.

11 CHAIRPERSON CHIN: Oh, okay.

12 ROBIN FENLEY: With that initiative, too,
13 DFTA is part of a task force that meets on a biweekly
14 basis with the other agencies as well. Currently,
15 one of the things that is being done is that all
16 of the 15 developments there are listening sessions
17 that are going on with people directly in the
18 community, and that information is also being brought
19 back to the task force, being brought back to the
20 different programs so that we can better know
21 individually what each development what is important
22 to them and what we need to focus on from a DFTA
23 perspective, from a caregiver perspective from
24 Grandparent Resource perspective.

1
2 CHAIRPERSON CHIN: Okay. [off mic]
3 finish all these questions. Okay. I mean, we have
4 other questions that we'll submit to you, because I'm
5 looking at the time. We have a lot of people who
6 wanted to testify. Any other--oh, we're joined by
7 Council Member Treyger. Do you have any questions
8 before I dismiss this question?

9 COUNCIL MEMBER TREYGER: [off mic]

10 CHAIRPERSON CHIN: Okay.

11 ROBIN FENLEY: Oh, great.

12 CHAIRPERSON CHIN: Well, one of the
13 things we'll be connecting with all the Council
14 Members to make sure that they know about your
15 program, that we can help publicize it. So, I thank
16 you for being here today.

17 ROBIN FENLEY: Thank you.

18 CHAIRPERSON CHIN: Next we want to call
19 up Reverend Johnson, Bobbie Sackman, James Arnold,
20 AARP, and Kevin Queen from New York Foundation for
21 Senior Citizens.

22 GREG JOHNSON: It's on? Okay, oh yes. We
23 don't have to--oh, alright. Good morning. Yes, I am
24 Reverend Greg Johnson, and as Reverend Greg Johnson
25 was asked to come, I wore this outfit. However, Greg

1 Johnson's going to speak. And that's as everyone in
2 the room is aware, I have been privileged for the
3 last 15 years to direct and create the care for the
4 family caregiver program through Emblem Health and
5 its foundation. I'm not going to read a statement.
6 Instead, I have given you back-up information. One
7 of the things that Emblem has done and allowed me to
8 do and every one of these fabulous people that you
9 have sitting before you who have done magic, who have
10 created incredible results with very little. They're
11 magicians, but they're family caregivers. We've all
12 worked together. Emblem has been the place that has
13 created platforms to create the New York City Family
14 Caregiver Coalition and now the New York City
15 Invitational, at this point, New York City
16 Partnership for Family Caregiving who are bringing
17 help to the corporations. I wanted to provide all of
18 you, as Council Members who are so important to this,
19 to welcome you to our world of family caregiving,
20 where the longest journey is from here to here, where
21 the greatest contribution that all of you can make is
22 to include in your vocabulary the words "family
23 caregiver." Wherever in the world I travel, I've
24 just come back from a major speaking trip in Asia, I
25

1 say the same two things, I have come to say the two
2 words that family caregivers rarely if ever here, and
3 that's thank you. And the world over, people
4 understand it. And I invite audiences. I'm going to
5 be doing it later this afternoon again at the United
6 Nations where I've spoken on a number of occasions,
7 and I have a speech that I did at the UN that I've
8 given to you because it has the informational sorts
9 of things that I think can inform your decisions,
10 give you the background on something that has not
11 been talked about, but rather assumed. We talk about
12 professional caregivers. We talk about the care
13 recipients, but healthcare is a three-legged stool,
14 and the third leg of that stool is the unpaid family
15 caregiver, of whom there are 500. I mean, there are
16 65.7 million in America bringing in and donating a
17 value of 522 billion US dollars every year, and when
18 I testify in Washington or at the state level,
19 wherever I speak, I'm here to say thank you, but I
20 also want these wonderful colleagues of mine sitting
21 here, and I love doing this in front of this
22 distinguished panel. Wherever in the world I go,
23 people are looking not only at America, but they are
24 looking at New York City, because we have led the way
25

1
2 in naming and knowing its many faces. And in that
3 simple statement is the greatest key that we need to
4 deal with. We need to name the family caregiver, and
5 to that end, within your books, and you don't need--
6 or the folder, is a book that I have the privilege of
7 co-authoring for the White House conference on aging
8 in 2005, and it was re--this addition is the 2010
9 because so much had happened, Care for the Family
10 Caregiver, a Place to Start. When I first was asked
11 by Emblem Health to create this program--yes, I'm an
12 ordained minister. The truth of the matter was I
13 said I don't know a great deal about this topic
14 academically, but as a minister, I have buried more
15 caregivers than care recipients. That is still true.
16 Now, part of that is because I have had the
17 privilege, the great privilege of working in this
18 world and doing thousands and thousands of speeches
19 all over. Some people think I would go to the
20 opening of a garage door if I could talk about family
21 caregiving, because I want to say thank you, but most
22 of all, I want people to name it, because until they
23 name it they can't do the one rule that is crucial
24 and central to family caregiving. And that's before
25 I can care for you, I've got to care for myself.

1
2 It's not selfish, it's needed. And that's the first
3 rule, and these people are the geniuses at providing
4 that to happen. Also, we need to know all the many
5 faces. It's not just old people like me or seniors
6 caring for seniors, the brilliant work of PSS. I
7 can't tell you how many places in the world I've
8 spoken where people have asked specifically about New
9 York's PSS.

10 CHAIRPERSON CHIN: Well, Reverend, I
11 really appreciate, you know, the work that you have
12 done. That's why we want to make sure that we have
13 time to hear from--

14 GREG JOHNSON: [INTERPOSING] Exactly,
15 and I will be very brief. All I am saying is I have
16 brought you information that I ask you to take and to
17 share. I would be pleased to share it with the rest
18 of the council. Two things: One, please name it.
19 And if you've ever campaigned on the corner of Eighth
20 Avenue and 23rd Street, yes, I've been the one who
21 came up and chatted with you and said, "Please don't
22 forget the family." I know you folks haven't, but
23 don't forget the family caregiver. Also, don't just
24 look at this as academic. You're a family caregiver.
25 We all will be. Roslyn Carter [sp?], probably says

1
2 it better than anyone, in life, there are really only
3 four type of people. There are those of us who are
4 family caregivers today. I'm one and many in this
5 room are. There are those who have been and those of
6 us who will be. And as a multiple stroke survivor, I
7 know the importance of being cared for. That's the
8 fourth category. We often play those roles
9 simultaneously. The support that you can give so
10 that the wonderful work that Doctor Corrado, the
11 Doctor Fenley, that Ali Hoden [sp?] bear, that Karen
12 Reznick [sp?] are leading the charge, because it
13 needs to be government, nonprofit and big business
14 working together, because we are all in this
15 together. So I hope that this will help you, and if
16 ever I can answer questions, I'm only too happy.

17 CHAIRPERSON CHIN: So, Bobby, we put
18 people on the clock to make sure that everyone get a
19 chance to testify. Thanks.

20 GREG JOHNSON: I'm going to excuse the
21 passage [off mic]. I'm sorry.

22 CHAIRPERSON CHIN: Thank you Reverend for
23 coming down.

24 BOBBIE SACKMAN: Well, I won't sound like
25 a minister, so we'll come down a little. I know,

1
2 even that's a hard act for even me to follow. Bobbie
3 Sackman, Council of Senior Centers and Services. I'm
4 just also not going to read through my testimony
5 that's written out. CSCS convenes the New York City
6 Family Caregiver Coalition and so it's an issue we've
7 worked on for many years. We released a report
8 about a year ago with AARP after--there were 12
9 listening sessions across the state from caregivers,
10 local service providers, local triple A's, and there
11 was--we have a report with various recommendations.
12 I've included a few of them in my testimony today.
13 And according to AARP from 2011 statistics, New York
14 State--in New York State, family caregivers are
15 providing 32 billion dollars' worth of free service.
16 SO there's a real economic impact on the state of the
17 backbone of the services, which are the families, and
18 it's women, and statistics show that by in large it's
19 women. It's not that men don't help. It's women,
20 and when they--and when it is a female caregiver,
21 they're doing more of the hands-on. They're doing
22 more of the--more hours. It's wives, daughters-in-
23 law, daughters continuing, and of course,
24 grandmothers raising grandparents for the most part.
25 So, the 21st century workforce issue for women is

1
2 access to elder care and supporting their caregiving,
3 and I would like to see City Council that every time
4 we talk, the City Council and everyone else talks
5 about childcare, that somebody says, "What about
6 elder care?" When they talk about the need for
7 access to affordable childcare of young mothers,
8 somebody says, what about the need for caregiver
9 supports and services for women who probably average
10 around 50, give or take. Again, a variety of ages,
11 but you know, pretty much it's the woman around that
12 age span. I think that's really important. It is
13 following what Greg said, that we have to get this
14 into the conversation. And what's in my report are a
15 lot of statistics broken down by various, you know,
16 Hispanic and African-American, other communities, so
17 I'm not going to go through that right now. And
18 there is a statement in there which I also had in my
19 immigrant testimony about the special needs of
20 immigrant families, people who not only the cultural
21 competency and the language, which is formidable
22 enough, but the fact that many aren't even eligible
23 for benefits. So, getting down to the
24 recommendations and the money. I couldn't agree with
25 more. Like many things in aging services, we do

1
2 miracles with almost nothing. So, we're requesting
3 as part of our budget priorities are three million
4 dollar, city funding of three million dollars through
5 the Department for the Aging and then out to the
6 contractors, you know, as described. Four million
7 dollars has been inadequate. It's a growing problem.
8 As everything you've heard today, it could also
9 include health for grandparents raising
10 grandchildren.

11 COUNCIL MEMBER TREYGER: You mean three
12 million on top of the four million?

13 BOBBIE SACKMAN: Absolutely three million
14 on top of the four million.

15 COUNCIL MEMBER TREYGER: We're not going
16 down, we're going forward.

17 BOBBIE SACKMAN: No, we ain't going down.
18 We can't go down, and just one more quick thing.
19 Another request we're going to have in the coming
20 year has to do with increasing funding for the NORC
21 [sic] program at NYCHA buildings, and I think in
22 connection with what you heard today about the
23 grandparent project that NORC's can help support on
24 an ongoing basis, you know, grandparent raising
25 grandchildren as well. So I just wanted to add that

1
2 in. And all the services we ask for always support
3 caregivers. Thank you.

4 CHAIRPERSON CHIN: Thank you, Bobbie.

5 Next?

6 JAMES ARNOLD: Good morning. James
7 Arnold, I'm a member of the Executive Council for the
8 AARP for the state of New York, and the only thing
9 important about that means I'm a volunteer and I
10 don't get paid for doing any of this. I've been
11 asked to--good thanks. I've been asked to read a
12 statement. It'll be a little more detailed than
13 either the forgoing did, but that's because I'm under
14 orders from headquarters to enter certain
15 documentation into the record. You have a copy of it
16 here. I want to thank you on behalf of our State
17 Director Beth Finkel and the 750,000 members of AARP
18 who are age 50 or older and who live in New York
19 City. We're glad to be able to go under the record
20 and to put in some detail work we've done with CSCS
21 and our own research and the numbers that we've
22 gathered across the state and our position on some of
23 these issues. Caregivers, of course, are people who
24 give care in our homes and communities to the parents
25 and the spouses and loved ones, and in doing so, they

1
2 make up the backbone AARP knows of our long term care
3 system. Our long term care system across the country
4 is not in very good shape, and we depend almost
5 completely, particularly here in New York City on the
6 volunteer efforts of caregivers to make that work.
7 Last year, in a run-up to the election, AARP surveyed
8 city voters who were 50 or older. We found 47
9 percent of those voters between the age of 50 and 64
10 who were working, and about four of every 10 of all
11 voters over the age of 50 are or have been family
12 caregivers in the past five years. That's over 1.1
13 million people in the New York City area. More than
14 half of the survey's respondents expect caregiving
15 responsibilities to follow them in the next five
16 years. That's 1.5 million people in this market.
17 And caregiving takes a toll. It has been alluded to
18 already. Two-thirds of working caregivers say their
19 caregiving responsibilities caused overwhelming or a
20 good deal of strain on their and their family's
21 quality of life, including financial hardship,
22 emotional stress and stress at work. Four of every
23 five of the respondents surveyed, caregivers and no
24 caregivers alike said strengthening laws and
25 regulations and funding services that support family

1
2 caregivers should be the top or a very high priority
3 for all of the city's elected officials. AARP
4 estimates that across New York State, more than 4.1
5 million people at any given time provide care that
6 would cost, as Bobbie said, over 32 billion dollars a
7 year if had to be paid for. SOSA [sic] for the New
8 York State Office of Aging estimates that 80 percent
9 of all long term care is provided by family members,
10 friends and neighbors. According to the SOSA survey
11 sustaining informal caregivers, New York State
12 caregivers support programs, without the services of
13 state programs supporting family caregivers, many
14 caregivers would be forced to place their loved ones
15 in institutional settings, like nursing homes, which
16 would largely be funded by tax payers through
17 Medicaid. AARP believes it's critical not only to
18 sustain these programs, but in fact to strengthen
19 them. As the baby boomer generation matures and the
20 number of young people proportionately decreases,
21 more of us will need care, but there will be fewer
22 family caregivers to provide it. This was a question
23 one of the Council Members asked earlier. Already,
24 the number of caregivers in New York has grown to 32
25 percent from 25 percent in 1990. A recent AARP

1
2 report found that while there are 6.6 potential
3 caregivers aged 45 to 64 for every person in the high
4 risk years of 80 plus in New York in 2010. There will
5 just be 4.8 in 2030. So, down from 6.6 to 4.8 by 2030
6 and only 3.5 by 2050.

7 CHAIRPERSON CHIN: Excuse me. We have
8 this on record, and it will be, because you have a
9 written testimony. So, would you like to sum up?

10 JAMES ARNOLD: Yes, let me just read the-
11 -at the end. I do want to pay a special tribute to
12 the work we did with CSCS and we're happy to join in
13 that recommendation in particular. So, we joined CSC
14 to urge support for allocating the three million
15 dollars for caregiving support services. We also ask
16 for yours and the Mayor's support for state
17 legislation to expand both paid and unpaid family
18 leave to family caregivers. AARP strongly supports
19 the Care Act, a bill in the state legislature that
20 would ensure family caregivers that are not only
21 included in medical records, but are provided live
22 care demonstrations prior to hospital discharge by
23 hospital staff to make sure they can adequately and
24 properly administer medications, dress wounds and
25 provide care to their loved ones at home, preventing

1
2 costly hospital readmissions. Lastly, AARP supports
3 CSCS requests that the city formerly track data on
4 caregivers to help you properly plan for their
5 growing numbers. All of these efforts would support
6 and sustain family caregivers, saving tax payers
7 money, preserving productivity in the workplace and
8 allowing parents, spouses and loved ones to age where
9 they want, which is right at home. Thank you.

10 CHAIRPERSON CHIN: Thank you.

11 KEVIN QUEEN: Morning, Council Members.

12 My name is Kevin Queen, excuse me. I'm Vice
13 President of New York Foundation for Senior Citizens.
14 I just want to speak briefly about a small but very
15 important program that we do operate that serves
16 caregivers. It's a citywide home sharing and respite
17 care program. Specifically, the respite care service
18 we've been doing for over two decades and it is--it
19 helps caregivers serve the frail, care for the frail
20 elderly at home at a very affordable rate of eight
21 dollars per hour. The program also provides
22 emergency respite care services to caregivers who
23 have a sudden inability to provide care week days
24 after 5:00 p.m., weekends, holidays, and in
25 emergencies. We're trying to always get the word

1
2 about the program. In the last two decades we've
3 served over 6,000 frail elderly and numerous of their
4 caregivers through this program. It is not a formal
5 contracted caregiver program. It's a program that
6 requires refunding annually, but it really has proven
7 cost effective services that are keeping seniors out
8 of institutional settings and avoiding emergencies
9 and really helping caregivers continue. So we
10 highlight this program among all of the other
11 caregiver programs to be considered and expanded over
12 time. Thank you.

13 CHAIRPERSON CHIN: Do you right now--for
14 this respite program that you provide, where do you
15 get the funding from?

16 KEVIN QUEEN: The funding is cobbled
17 together, as we say. We receive discretionary money
18 from City Council Members, the citywide discretionary
19 funds as well from individual Council Members. We do
20 have some state money from SOFA [sic] and then the
21 Governor's budget, and we do have small contract with
22 the Department for the Aging because we map--we put
23 our home sharing service and our respite care service
24 together as one program.

25

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2 CHAIRPERSON CHIN: Okay. I think we
3 should try to get more information and see if we
4 could get more support for that program.

5 KEVIN QUEEN: Thank you.

6 CHAIRPERSON CHIN: Thank you.

7 COUNCIL MEMBER TREYGER: Thank you,
8 Chair. Just a quick question to the panel. Anyone
9 could answer. There's certainly a tremendous need
10 for additional resources for caregivers. We have a
11 population certainly that could certainly needs not
12 just wants, but needs this care. The one thing,
13 though, I'd like to hear more about, we often speak
14 obviously of those who are enjoying the golden years
15 of their lives and should enjoy the golden years of
16 their lives, but the state in recent years has been
17 mandated by the federal government to transition
18 people out of psychiatric institutions back into main
19 stream society as much possible in the least
20 restrictive environments. Can anyone speak to the
21 caregiving to those individuals who might not be
22 senior citizen age, but are adults and have difficult
23 time being self-sufficient at home? What is the--
24 where are we at with that? If anyone could speak to

1
2 the caregiving offered to people with mental
3 disabilities.

4 BOBBIE SACKMAN: Are you talking--I'm
5 sorry, are you talking about that the caregiver is
6 under 55 or 60?

7 COUNCIL MEMBER TREYGER: No, whether the
8 recipients of the care and the type of care they're
9 receiving, and you know, is it enough attention being
10 paid to this issue?

11 BOBBIE SACKMAN: Yeah, I don't--I can't
12 answer that question. Sorry. This targets
13 definitely, you know, an older population. The needs
14 are--although, DFTA said something about--didn't you
15 guys say something about that you serve people who
16 are raising adult children with disabilities and all
17 that, or? Yeah, yeah, so I don't know if there's
18 some way it could mesh with the DFTA system, but I
19 don't--

20 COUNCIL MEMBER TREYGER: [interposing]
21 The reason why I raise this is because if you look at
22 many of the populations living in these almost like
23 these outpatient clinics. Many of them are, you
24 know, older adults, some seniors, and as they try to
25 mainstream them back into society as much as

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2 possible, I'm concerned about what types of services
3 and care they receive at home?

4 BOBBIE SACKMAN: The focus of the
5 caregiver program, I mean, you're identifying
6 obviously a serious need, but the focus of the
7 caregiver program is the caregiver.

8 COUNCIL MEMBER TREYGER: Right.

9 BOBBIE SACKMAN: Which is something that
10 makes it unique. And while you want the care
11 recipient to receive services, obviously that they
12 need.

13 COUNCIL MEMBER TREYGER: Right.

14 BOBBIE SACKMAN: That's what we all
15 advocate for. What's so unique about this program
16 and the beauty of the flexibility of this program has
17 had is that really the "client" is the caregiver.

18 COUNCIL MEMBER TREYGER: Right.

19 BOBBIE SACKMAN: So, I don't know, again-

20 -

21 COUNCIL MEMBER TREYGER: [interposing]

22 Well, I--

23 BOBBIE SACKMAN: how that quite measures
24 with what you're looking for.

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2 COUNCIL MEMBER TREYGER: I, again--what
3 I'm saying is I think that we're trying to identify
4 and trying to really strengthen an area that I think
5 also deserves a lot of care, and I think that
6 caregivers, no question about it, they really do
7 God's work in my opinion, and we have to support them
8 any way we can. But I think an area that where the
9 government has fallen short is in the issue of mental
10 health, and many times we speak about people who face
11 physical ailments, which is certainly a very huge
12 issue, but I think that mental health is also very
13 important. And I think that we have fallen short
14 from the government's side in addressing that very
15 serious need to provide care for people who need it
16 the most.

17 BOBBIE SACKMAN: Nobody would argue with
18 that, yeah.

19 CHAIRPERSON CHIN: I think for the
20 caregiver, if they have family members that have
21 mental issues, whatever, then they can also reach out
22 to find the resources that can support them so that
23 they can help support their family members. So I
24 think that DFTA has the programs that we can make
25 sure that people know about, and that's the whole

1
2 thing about education and outreach so that family
3 members know that these programs are available. The
4 question I have for the panel here is that have you
5 worked closely with DFTA's the program, the caregiver
6 program that they have?

7 KEVIN QUEEN: We actually receive many
8 referrals directly from DFTA as well as from the
9 caregiver programs. We share information. We also
10 do as part of our respite and home sharing program,
11 thousands of information and referral every year for
12 people that are calling in that, you know, are either
13 going to use the service immediately or later on or
14 we can share other resources. So there's a lot of
15 cross-referral that does happen, which really helps
16 to, you know, identify and meet various needs that
17 come up during the course of someone making an
18 original or initial request for service. You
19 identify other services that they may actually need.

20 BOBBIE SACKMAN: I think there are other
21 people who are going to be speaking who are direct
22 service providers and might be better, you know, able
23 to answer, but on a policy advocacy level CSCS's
24 membership includes the organizations that receive
25 the contracts from DFTA in terms of caregiving. So

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2 this is--that's why this is a priority for us, but
3 again, I see people in the room here who I have a
4 feeling could really answer that question like Kevin
5 was able to answer it.

6 CHAIRPERSON CHIN: Great. Thank you.
7 Well, thank you to this panel. Next we're going to
8 call up Alicia Fry from SNAP, Services Now for Adult
9 Person, Barbara Graves-Poller from MFY Legal Services
10 and Erin Brennan from Selfhealth Community Services.
11 Okay, if I pronounced your name wrong, please correct
12 me. Shavani? Oh, Shyvonno Noboa from the Sunnyside
13 Community Services. Thank you for being here.

14 ALICIA FRY: Ready?

15 CHAIRPERSON CHIN: Yes, you may begin.

16 ALICIA FRY: Okay, good morning
17 Chairwoman Chin and distinguished members of the City
18 Council Committee on Aging. Thank you for conducting
19 this hearing on this rainy morning. My name is
20 Alicia Fry, and I'm the Clinical Case Management
21 Director of Services Now for Adult Persons, Inc.,
22 also known as SNAP. I am here representing Marie
23 Ellen Galasso. She is SNAP's Director of Social
24 Services, and she oversees SNAP's caregiver program.
25 She is also the Chair of the New York City Family

1
2 Caregiver Coalition, which is a program of the
3 Council of Senior Centers and Services and she is
4 familiar with caregiver issues both professionally
5 and personally, as am I. And I'd like to add that
6 she is also my mentor and she's who I want to be when
7 I grow up. The issue of caregiving in New York City
8 and across the nation is quickly becoming one of the
9 most crucial issues of our time, with approximately
10 well over 42 million Americans providing care for our
11 relative or friend with a chronic health condition,
12 it becomes quite evident that we must be proactive in
13 our support of informal caregivers before we find
14 ourselves reacting to a crisis of epidemic
15 proportions. In fact, I suspect that we would be,
16 that all of us would be hard pressed to find even one
17 person within our own personal circles who has not
18 provided care for a loved one or friend at some point
19 in time. The current caregiver support funding
20 services come through the federal Older Americans
21 Act, and allow community agencies like SNAP to
22 provide caregivers with needed supportive services
23 such as counseling, support groups, training, limited
24 and temporary home care, and/or group care for care
25 receivers which allows caregivers to have a much

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2 needed respite from their caregiving
3 responsibilities. While these services are helpful,
4 budgets are severely limited. To give a better
5 perspective on budget limitations, in order for SNAP
6 to provide respite services to all of the caregiver
7 clients requesting them, respite can only be offered
8 twice a month, and that's four hours two times per
9 month up to a maximum of approximately three months
10 per client. The rest of the time they're on their
11 own. As this shows the need for caregiver support,
12 the need for caregiver support far outweighs our
13 current capacity to provider services and this gap
14 continues to increase. The enormity of this issue
15 speaks to the necessity of increasing and base lining
16 caregiver support funding. It should be noted that
17 caregivers support and aging services complement each
18 other. Services for older adults such as case
19 management, home delivered meals, home care, also
20 known as ISEP [sic], and social adult daycare not
21 only help the older client, but also assist the
22 caregiver in keeping their loved ones in the home.
23 Funding for both caregiver support and aging services
24 working together help keep older adults in the
25 community. This is far less costly than placing a

1
2 loved one in an institutional setting such as a
3 nursing home and represents what the majority of
4 older adults want for themselves. According to a
5 recent national survey, due to caregiver
6 responsibilities one in five caregiver retirees left
7 the workforce earlier than they had planned. Seven
8 in ten had to make work adjustments, which included
9 cutting back on work hours, changing jobs and/or
10 stopping work completely. Low income workers, women
11 and persons of color were often most likely to reduce
12 work hours or leave the workforce completely due to
13 caregiving needs. Without support, caregiving is not
14 only financially costly on the system, but
15 perpetuates poverty for the future as caregivers
16 forgo present earnings and future social security
17 benefits. These reductions in work hours can have
18 long term detrimental consequences. This speaks to
19 the need for state legislation to expand both paid
20 and unpaid family leave while also addressing the
21 need for workplace flexibility. Access to affordable
22 legal assistance, along with training for caregivers
23 from hospital staff at discharge are also ways to
24 support family caregivers and diminish both emotional
25 and financial stress and to prevent readmission.

1
2 Providing support services for caregivers is key to
3 their wellbeing and demonstrates fiscal and moral
4 responsibility and integrity. We appreciate the
5 opportunity to speak to all of you today, and know
6 that you will work hard on behalf of caregivers in
7 New York City and throughout the state. And may I
8 end with a completely non-sectarian comment, blessed
9 are the caregivers, for they shall inherit the earth.
10 Thank you.

11 BARBARA GRAVES-POLLER: Thank you for
12 allowing us to testify here today. My name is
13 Barbara Graves-Poller, and I supervise the Kinship
14 Caregiver Law Project at MFY Legal Services. MFY's
15 Kinship Care Project represents and counsels New
16 Yorkers who serve as defacto parents for children.
17 MFY's is the only civil legal services program in the
18 city, and in fact, in the state that specifically
19 dedicated to the legal needs of the kinship
20 caregivers, and those are people who are caring for
21 children, grandparents, other relatives who are not
22 the biological mother and father of the child. We
23 also co-chair the New York City Kin-Care [sic]
24 taskforce, and that is a group of advocates,
25 representatives from city agencies and social service

1 providers who gather to address policy issues that
2 face the kinship care community faces. While most
3 of my comments will focus on the Grandparent Resource
4 Center's work with kinship caregivers, I'd like to
5 note that MFY also works closely with DFTA to serve
6 the legal needs of seniors to ensure that they age in
7 place with dignity. Much of this work involves
8 representing seniors in eviction prevention
9 proceedings so that they do not lose their apartments
10 and become forced to live in institutions like adult
11 homes and nursing homes. We also help to obtain
12 public benefits, in-home care so that seniors can
13 maintain their community housing. The prior testimony
14 already described the increase in grandparents and
15 other relatives who are caring for children, but it's
16 important to put this type of caregiving in a broader
17 context, and this caregiving may differ somewhat from
18 other forms of caregiving. In New York as in other
19 areas of the country, the need for kinship care most
20 often arises in communities with high levels of
21 poverty, teen pregnancy, mental illness, parental
22 incarceration, and inadequate family support
23 services. Approximately three-quarters of all
24 caregiving grandparents live near or below the
25

1 poverty line. Throughout the state, 80 percent of
2 all kinship caregivers are African-American or
3 Latino, 64 percent are unmarried women, and 85
4 percent receive no financial support from the child's
5 parents. What we see in our practice shows that in
6 New York City, caregivers are both younger and poorer
7 than their statewide counterparts. This combination
8 of factors places low income kinship care givers and
9 care giving families at extreme risk of replicating
10 the cycle of intergenerational poverty. These are
11 families with insufficient resources to navigate our
12 Family Court and immigration systems, and they're
13 also households in which the adverse experiences
14 suffered by the children and the emotional trauma and
15 stressors of caregiving impair the family's mental
16 and physical health. The holistic legal services in
17 areas of custody, guardianship, immigration,
18 challenging foster care placements, this is what MFY
19 provides, and we provide them in collaboration with
20 DFTA and other social service providers. These are
21 essential to preventing these families from suffering
22 additional crisis. For years, representatives from
23 the Grandparent Resource Center including Helen
24 Flowers [sic] and Brandy Orange [sic], they've played
25

1
2 a key role in advancing policies to support
3 caregivers, but moving forward, to talk about some of
4 the gaps in those services, I just want to highlight
5 a couple of things. This is a real one-stop shop for
6 caregivers. Unfortunately, the shop lacks adequate
7 resources to serve all of New York's caregiving
8 community. Beyond that, the Grandparent Resource
9 Center is located in a--is an agency within an agency
10 to serve seniors, but many grandparent caregivers are
11 not yet senior citizens. We represent, for example,
12 a 43 year old grandmother in the Bronx who's caring
13 for an infant recently born to her incarcerated
14 daughter. A client like that probably would not know
15 about or think that she's eligible for services from
16 the Grandparent Resource Center, and given the
17 demographics of New York City caregivers, it's
18 important for the GRC to both increase outreach and
19 services to expressly include non-grandparent
20 caregivers in its outreach materials and 311 listing,
21 and also clarify that there's no hard and fast age
22 requirement to receive services from the Grandparent
23 Resource Center, because many people who need,
24 desperately need these services believe that they are
25 not currently eligible.

1
2 ERIN BRENNAN: Good morning. My name is
3 Erin Brennan, and I'm the Program Director of the
4 Selfhelp Alzheimer's Resource Program, which we call
5 SHARP. Throughout the extensive services that
6 Selfhelp provides, many of our programs encounter
7 individuals who provide caregiving service to a
8 family member. Many of these caregivers are adult
9 children who are juggling the responsibilities of
10 caring for an elderly parent, raising their own
11 families and working outside the home to support
12 their families. I imagine that many of you in this
13 room would find yourselves with this challenging
14 situation as well. Others or individuals who are
15 aging themselves and find it increasingly challenge
16 to live with and care for their affected spouses.
17 Selfhelp's SHARP program is a social adult day
18 program for individuals with Alzheimer's disease,
19 dementia and other memory impairments. The program
20 provides socialization and stimulation to individuals
21 with memory impairment, while providing the
22 caregivers with a much needed break from their
23 caregiving responsibilities. This allows the
24 caregiver to recharge their batteries so that they
25 can continue to care for their loved one for as long

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2 as possible. The SHARP program also provides a
3 caregiver support group where caregivers can come
4 together to share experiences as well as to learn and
5 support each other. Councilman Chin, you had
6 mentioned about social adult day earlier, and I think
7 a lot of people miss that piece as part of the
8 caregiving solution, shall I say, but social adult
9 day programs provide services who enable individuals
10 to continue living in the community for as long as
11 possible, and caregiver support is a critical aspect
12 of these services. The New York City Department for
13 the aging provides funding to caregiver programs
14 throughout the city of New York. The services
15 provided by these programs are invaluable. As
16 resident of New York City continue to live longer, we
17 urge the New York City Council to respond to the
18 increasing needs of this population by increasing the
19 funding for caregiving services. I thank you for
20 giving us the opportunity to present this testimony.
21 And there's more in there. I just kind of highlighted
22 what was really important.

23 CHAIRPERSON CHIN: Thank you. Oh, next.

24 UNIDENTIFIED: I could hear you from
25 here. Did you have a question?

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CHAIRPERSON CHIN: Oh.

SHYVONNE NOBOA: Hi, so, good morning
Chairperson Chin and Council Members. I want to
thank you for having us here today. My name is
Shyvonne Noboa. I'm a social worker and Director of
the Western Queens Caregiver Network at Sunnyside
Community Services. We're one of the CBO's that
receives the caregiver contract from DFTA, as well as
one of the oldest settlement houses in Queens. I'm
here also representing the organizations of the
network proposed of HANAC and Queens Community House.
Support from the Department for the aging towards
caregiver support is an essential service in our
community, and today, I call upon you to increase
this much needed funded stream. I don't think I'm
out of line when I say every caregiver in Western
Queens would certainly back Bobbie and CSCS's request
to increase funding for three million dollars. The
program and services and support services that we
provide lessen the strain informal family caregivers
experience in their roles. We serve approximately
550 individuals each year, including those who are
primarily caregiver to an individuals over the age of
60, grandparents who are 55 years old or raising a

1 grandchild, and individuals over the age of 60 caring
2 for disabled adult. We provide individual and group
3 counseling, caregiving skills, training workshops and
4 psycho educational education sessions, assistance in
5 accessing benefits and entitlements as well as
6 individual and group respite. Our network is able to
7 provide services in English, Spanish, Russian, and
8 Greek. Before reaching us, caregivers have been
9 burned out, stressed out and have reached a breaking
10 point. Our caregivers have repeatedly told us that
11 our program and support services offered were and
12 continued to be life changing. So, I'm going to give
13 you an example of one of our caregivers who is Maria,
14 whose mother is in the early stages of Alzheimer's
15 disease. Maria is an only child with no one to share
16 the responsibility and duties of family caregiving.
17 Maria checks in on her mother daily, shops for her,
18 manages her finances, and advocates on her mother's
19 behalf. She accompanies her mother on all medical
20 appointments. She is a public school teacher and
21 must continue to work. She has reached to--she
22 reached out to us when she realized she needed
23 additional support and was overwhelmed trying to plan
24 for the future as her disease progresses. Our
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2 caregiver program helped Maria through the complex,
3 and I highlight complex, process to obtain Medicaid,
4 long term care services, helping her gather necessary
5 documents and completing and submitting applications
6 for Medicaid ensuring that they didn't fall through
7 the loop hole. We then helped her complete and
8 submit an application for a pooled income trust to
9 manage the mother's Medicaid surplus and submitted
10 documents to Medicaid. Her mother began attending
11 our social adult day program several times a week.
12 Maria's mother is enjoying from the programing and
13 benefiting from social engagement and just as
14 important, Maria knows that her mother is in a safe
15 environment while she is at work and can focus her
16 attention there. With our support, they've enrolled
17 in a managed long term care plan and now receive home
18 care services. The dedicated worker is assisting
19 Maria's mom in her daily needs and keeping her safe.
20 All of this has profoundly changed Maria's life and
21 she now feels she has the resources needed to
22 continue to care for her mom. And I have also
23 submitted testimony from Blanca Entrone [sp?] who is
24 one of our longest support group members. I'm just
25 going to highlight two passages from her letter. So

1
2 Blanca, and I quote "does mostly everything for my
3 mom, who has been diagnosed with mid-stage dementia.
4 I do her laundry, shopping, bills, letters, phone
5 calls, doctor's appointments. It's been very tiring,
6 time consuming, frustrating, exhausting time, but
7 there are also moments that can be quite rewarding.
8 There are never enough hours in the day to do all the
9 things that entail taking care of a person with
10 dementia. Most of the time one has to sit and
11 reassure the parent everything's okay, calm them down
12 because they're so lost and confused. I've been
13 extremely fortunate to belong to a support group
14 that's been valuable to me. They provide help,
15 comfort and a great sounding board. I don't know
16 what I would do without them. They have become my
17 family and mean a lot. I would be completely lost
18 without them. They are my rock." So I just want to
19 share that this is one of hundreds of examples that
20 we can give you with regards to the complexity of
21 situations and profound impact our services have on
22 the lives of many of our informal caregivers, and I
23 want to thank for again giving us this opportunity,
24 allowing me to speak with you today and for your

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2 continued support to New York City caregivers and
3 older adults. Thank you.

4 CHAIRPERSON CHIN: Thank you all for
5 being here today. Can you tell me maybe some of a
6 little bit about your working relationship with DFTA
7 in terms of getting support that your program needs,
8 besides the contract if you have a contract with
9 them?

10 SHYVONNE NOBOA: We do. We certainly
11 look upon DFTA as our partner and, you know, as our
12 main funding source. We look for them for guidance.
13 We look for them for the information.

14 CHAIRPERSON CHIN: Do they also do
15 referrals directly to you?

16 SHYVONNE NOBOA: They do. So we'll often
17 times receive a referral from, whether it's GRC or
18 the Alzheimer's Resource Center saying hey, we got a
19 call come through 311. They're in your area, because
20 of course, we're restricted to provide services in
21 our catchment area. So it's a working relationship
22 vise versa. As I said, it's a partnership. We do
23 have a new system peer place where we have to put in
24 all of the information, all the tracking, as Robin
25 said, all the bean counting, which I'll share takes

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2 away from the real service that we're providing, but
3 I do understand that data entry is important so that
4 we have this evidence based information. We
5 certainly seek support for more funding to enhance
6 staffing. It is extremely difficult. Not only do I
7 direct the program and oversee two other
8 subcontractors, I carry a case load of 58 Spanish
9 speaking clients. So, it's a challenge, and we take
10 it day by day.

11 CHAIRPERSON CHIN: Now, for this fiscal
12 year the Council was able to add some additional
13 funding to the Real Social Adult Daycare. So with
14 the additional funding, will you guy--were you able
15 to provide, you know, extra hours, or?

16 SHYVONNE NOBOA: So, I believe our social
17 adult day program at Sunnyside Community Services has
18 received some DFTA funding, but providing service
19 through social adult day requires either a person's
20 ability to privately pay, which is increasingly
21 difficult. We were talking about, you know, people
22 who have retired, low social security, no pension due
23 to lack of language, access to education. Their
24 retirement benefits aren't a lot, and so they rely on
25 our assistance to enroll them in Medicaid managed

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2 long term care, which is going to cover those
3 services. So, it's a help. Any dollar that comes
4 through does help, but really the increased funding
5 for respite and group respite would go--would take--
6 would skyrocket us.

7 CHAIRPERSON CHIN: Okay. I mean, that's
8 the issue that we're looking at right now, because
9 you have all those pop-up social day care that are
10 not really providing the quality service, and a lot
11 of these long term managed care contracts are
12 contracting with them versus, you know, helping the
13 really good ones. So, we're continuing to try to
14 monitor that. But thank you all for coming in today.

15 ERIN BRENNAN: Can I just say one thing?

16 CHAIRPERSON CHIN: Yes.

17 ERIN BRENNAN: You had mentioned about
18 the social adult day. Selfhelp did receive the City
19 Council funding, which allowed us to expand our
20 program to five days, and because we get this city
21 funding and it comes to the Department of the Aging,
22 that allows people to come to the program on a
23 contribution basis, which for some people they shy
24 away from private paid programs. So it really allows
25 those people who are on the lower income end of it

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2 and are not eligible for Medicaid at this point or
3 don't want to apply for Medicaid to actually come to
4 the program as well. So we've been able to expand
5 our services with the support and the funding that
6 we've gotten from the City Council.

7 CHAIRPERSON CHIN: Good.

8 ERIN BRENNAN: We do appreciate that.

9 CHAIRPERSON CHIN: Yes, good to hear.

10 Thank you. Thank you for coming today. Okay, this
11 is the last panel. Is that Rimas Jasin? Oh. The
12 PSS Grandparent Family Apartments. Julie Willig from
13 Heights and Hills, and Molly Krokoscowitz [sic], Kos-
14 -sorry, Kosky [sic] from JASA [sic]. Thank you for
15 coming in today. Please begin.

16 RIMAS JASIN: Okay, well thank you. My
17 name's Rimas Jasin. I'm Executive Director of PSS,
18 and I'm also Chair of the New York State Kinicare
19 Coalition. I'm really here--I'll be very brief. I'm
20 here to share three thank you's, two invitations and
21 one suggestion. The three thank you's is first thank
22 you for recognizing the importance of family
23 caregiving and holding this hearing and providing
24 this opportunity to provide testimony. Also, I want
25 to thank all the Council Members for their support

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2 over the years. The discretionary funds are needed
3 and are important to agencies such as PSS. And the
4 third I want to thank also the city agencies that
5 fund organizations like PSS, organizations like DFTA
6 and other agencies in the city here. I never miss an
7 opportunity to thank funders, especially when I think
8 some of them might be in the room or were. Two, the
9 invitations. In 2015, the Grandparent Family
10 Apartments are going to be celebrating their 10th
11 anniversary. We're the only building of its kind, a
12 little in the country, and we've been there working
13 with these kinship caregivers every day, every hour
14 of every day over the last 10 years. We've seen our
15 families grow and evolve. We've seen our children
16 grow up, our grandparents grow older and families
17 move on to lives elsewhere. And we're very proud of
18 that fact, and so the two invitations are that we'll
19 be holding some special events in our 10th
20 anniversary next year, and we're going to be inviting
21 Council Members to those events. And secondly, just
22 an open invitation to come and visit the GFA at any
23 time. I've included in your packet an article that
24 was in a Swiss magazine in French. You get to
25 practice your high school French possibly. So we

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2 have people and visitors from all over the world
3 visit the Grandparent Family Apartments because of
4 unique program that it is and the innovative services
5 that are located there. And then finally then, just
6 the suggestion. You've heard a lot of data, a lot of
7 information from the previous speakers. I'm not
8 going to go over those, but I gather from what you've
9 heard from them is the fact that kinship caregiving,
10 family caregiving is a multidimensional issue, and so
11 my one recommendation would be that we work with
12 funding agencies to create multidimensional and
13 comprehensive and strategic funding opportunities.
14 All too often the funding opportunities that we see
15 come out are only providing funding for a very narrow
16 slice of one of the issues, and I've listed a variety
17 of issues there. A good example is DYCD. They'll
18 put out an RFP for academic support. We would try
19 to--we could try to go after those funds, but it's
20 only for the ages maybe 12 to 13, only from three to
21 five, only in a school setting or a community based
22 setting. My question is then, what happens with our
23 youth once they reach age 14? There's literally no
24 seamless opportunities to fund the programming for

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2 these youth as they get older or the families as
3 their needs change and evolve over time. Thank you.

4 CHAIRPERSON CHIN: Thank you. We've also
5 been joined by Council Member Arroyo, who herself is
6 a caregiver, right? Taking care of her grandchildren.
7 Next?

8 JUDY WILLIG: Good morning, or I should
9 say good afternoon. My name is Judy Willig. For 28
10 years I've been the Executive Director of Heights and
11 Hills, an organization in Brooklyn that serves over
12 4,000 people a year, including their families. I'm
13 going to--one of the things about battling clean-up
14 here is I'm not going to go over all the things that
15 my colleagues have stated. The only other thing I
16 want to add, first of all, is that I myself am a
17 caregiver for my 91 year old mother, and stepping
18 into that role after 20 years as a professional was a
19 complete eye opener. That said, I want to talk a
20 little bit--oh, one more thing, which is I am a
21 member of a support group, and I could not do what I
22 do for my mom without that support. So that is a key
23 kind of a support for family caregivers. Back to my
24 professional hat, we are one of the DFTA funded
25 programs. We serve over 500 family caregivers

1 ongoing through the year, and then many more hundreds
2 by providing one time information kinds of services.
3 In addition to all the services you've heard about
4 that DFTA funds, we also do a lot of seminars,
5 community seminars. So we provide, and I give you a
6 sample in caregiving 101, caregiving for the sandwich
7 generation, some of my favorites, how to care for
8 your loved one when they are not so loveable,
9 caregiving and family, staying sane when everyone
10 else is not on the same page. These are the kinds of
11 issues that family caregivers are struggling with all
12 the time. We are one of the DFTA funded providers
13 that provide an array of services, and caregiving
14 support is so integral to all the other services.
15 Thirty percent of our referrals to our caregiver
16 program come from our case management program, our
17 care transitions program, and the message here is
18 that it's all of these services put together that
19 allow families to continue to be the main providers
20 of service. Our other referrals come through 311,
21 through DFTA, from professionals in the community
22 that we reach out to constantly, and also by word of
23 mouth, often from other caregivers. As my colleagues
24 have all talked about, a huge issue is the lack of
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1 self-identification. Caregivers don't think of
2 themselves as caregivers. They are just people who
3 are doing what they have to do for their loved ones,
4 and that's a huge issue, because people don't realize
5 that there are formal services out there for them and
6 that what they are doing is something that needs to
7 be supported. I'm not going to talk about the
8 research. You've heard all about all of that. What
9 I do want to stress is the need for flexibility. You
10 talked about that in terms of flexibility, a funding,
11 but also flexibility in terms of the requirements to
12 provide the services. Caregivers come in all sizes
13 and shapes and ages. A little more than half the
14 people we see are children of aging family members,
15 most of whom are working. The other half are
16 spouses. Clearly, one size does not fit all. We
17 provide support groups, some that are mainly spouses.
18 We provide telephone support groups for working
19 caregivers in the evening. The greatest problem of
20 all of our caregivers is the lack of adequate
21 resources. We particularly in New York City where we
22 pride ourselves on being the great innovators, we
23 have a real severe lack of options. Medicaid
24 homecare is now under managed care shrinking.
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1 Families are having to fill in the gaps, and for
2 people who are above Medicaid eligibility, the
3 options are really very limited. So that you find a
4 lot of caregivers are not just emotionally supporting
5 and physically supporting, but financially supporting
6 their loved ones, which has implications for their
7 own aging and retirement. I want to talk a little
8 bit just quickly about recommendations. Everybody's
9 talked about funding. I'm preaching to the choir,
10 but we need to continue to increase funding for the
11 growing population of elders. We need legislation to
12 support family leave and workplace flexibility. I
13 have to leave work early this afternoon because
14 there's some Christmas event where my mother lives,
15 and as a family member I need to go and meet with the
16 staff and show my support, because of course, people
17 who have involved family get treated better than
18 people who are all alone. Finally, two more things.
19 A public services campaign--the commercials we see
20 against smoking are brilliant. Why are we not doing
21 something like that for caregivers? Letting people
22 understand that they're not alone in this. And the
23 final question and my final comment, and it answers
24 some of your question, Council Member Chin,
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1 flexibility is critical, and Bobbie talked about the
2 need for data, and I agree. We need data collection,
3 but we need to do it in a way that we are not
4 burdening family members with more requirements. I'm
5 a little concerned because of late DFTA is talking
6 about additional requirements of the caregiver
7 programs, requesting more frequent assessments and
8 paperwork, and we find in a service where the
9 caregiver is the client the approach needs to be
10 different than when you are dealing with the care
11 recipient or the elder. And we need to be respectful
12 of people's time, their lack of emotional
13 availability, but also their privacy. My final words
14 are, it's in government's best interest to support
15 families and provide them with the tools they need.
16 Not only is it cost effective, but it's the right
17 thing to do, and I thank you.

19 MOLLY KRAKOWSKI: Hi, my name is Molly
20 Krakowski. I'm the Director of Legislative Affairs
21 at JASA, and I want to thank Council Member Chin,
22 Chair Chin, for this important hearing. I too will
23 skip ahead a bit. JASA, as you know, is a rather
24 large social service agency and our mission is to
25 allow older adults to age in place with dignity and

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2 autonomy. And we have a DFTA funded caregiver
3 respite program in Brooklyn. We serve more than
4 1,000 individuals each year. We help them, family
5 caregivers with services such as in-home group
6 respite care, individual counseling, access to
7 benefits and entitlements, etcetera, and we have an
8 extensive outreach, educational outreach program
9 through JASA's Brooklyn caregiver respite program
10 that also helps to promote the community awareness
11 about family caregiver needs and available resources.
12 So I'll be reaching out to Council Member Deutsch who
13 I know mentioned that he wasn't aware of some of
14 those services. What I wanted to highlight actually
15 is that obviously there's a need for additional
16 funding, and any additional funding will be very
17 welcomed, but one of--two of the things that we've
18 done without that funding, which I think are worth
19 highlighting. In 2009 we received a grant from UJ
20 [sic] Federation to initiate a volunteer based
21 caregiver assistance project. It's the caregiver
22 mentor cooperative, and the idea was to engage former
23 caregivers and to have them help us mentor current
24 caregivers in what they're facing. And there are
25 approximately 60 successful mentor volunteer new

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2 caregiver matches that were made during that three
3 year pilot project. More recently we secured a grant
4 from Met Life Innovations in Caregiving Program
5 called JASA Connections, also in several Brooklyn
6 communities. And the idea, again, was to set up
7 mentoring programs to expand and include evidence
8 based projects and to specifically focus on people
9 with dementia. And the goal of the program to
10 improve the quality of life for caregivers and people
11 diagnosed with Alzheimer's disease and related
12 disorders through a partner volunteer and home
13 intervention. And so during the short existence of
14 that funding we've identified and successfully
15 matched 13 mentor caregivers and we have three
16 additional ones currently going through that process.
17 What they were able to do in addition to just some of
18 the walking people through what it all entails and
19 helping them through it was also to engage the care
20 recipient in meaningful activities, creating memory
21 boxes, discussions, specific period music listening,
22 and some of the things that maybe they would have
23 gotten in other settings, but through this volunteer
24 program. So while we appreciate DFTA funding that
25 allows JASA to offer a range of services available to

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2 caregivers through the Brooklyn Caregivers Respite
3 Program, we've also tried to come up with some
4 innovative ways to reach without the funding, and
5 anything that we do would require funding to continue
6 doing even those programs where we do try and engage
7 more volunteers and save funding. There's still a
8 critical need for funding. Support for family
9 caregivers is a vital component to caring society's
10 commitment to its aging members. It saves the public
11 money. It deflects unneeded use of hospital
12 emergency rooms, nursing homes and other costly
13 institutions, and it allows family members to play an
14 active role in caring for their loved ones. We hope
15 this leads to further discussions. Certainly we
16 would support any increase in funding and we're happy
17 to be of support.

18 CHAIRPERSON CHIN: I really appreciate
19 all of you for coming and all the great work that you
20 are doing. And hopefully, this will inform us, right
21 Bobbie, in the budget process and to really highlight
22 the importance of caregivers and see how as a city
23 that we can build more support for that. So thank
24 you very much for coming in today. And I want to
25 thank all of you for coming in, and we're going to be

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COMMITTEE ON AGING

continuing to work on this issue. And the hearing is
adjourned. Thank you.

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COMMITTEE ON AGING

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 10, 2014