


Steps for Conducting and Outcomes of the NYC Informal Caregiver Survey

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The slide features the NYC Department for the Aging logo on the left. To its right are three small, square diagrams arranged horizontally, each containing a simplified human figure with lines indicating different parts of the body or survey components.

Agenda

- ▶ Background
- ▶ Process
- ▶ Key Findings
- ▶ Recommendations
- ▶ Where We are Today

Background

- ▶ August of 2016, NYC City Council passed LL 97 of 2016 which required DFTA to develop and conduct a survey of unpaid caregivers in New York City. It also requires DFTA to create a "comprehensive plan" that addresses the needs of unpaid caregivers.
- ▶ The Council identified three categories of caregivers:
 - ▶ Adults caring for family member(s) aged 60 or older, including adults with Alzheimer's disease or other dementia;
 - ▶ Grandparents or other older relatives who are the primary caregivers of people younger than 18; and
 - ▶ Adults caring for people with disabilities between the 18 and 59.

Focus of Study

- ▶ To what extent do the three groups of unpaid caregivers obtain the services they need?
- ▶ What barriers do unpaid caregivers face in obtaining support services?

Process Stage 1: Study Design and Methods Established

- ▶ **Fall of 2016:**
 - ▶ Small interagency workgroup met weekly to drive the project. Members include: DFTA, ACS, MOPD and OPS
 - ▶ Study design determined.
 - ▶ Convened external stakeholders in February and July of 2016.
- ▶ **Winter of 2016:**
 - ▶ Contracted with Westat, an external firm, as the research lead for the project.
 - ▶ Survey was developed.

Process Stage 2: Survey NYC Caregivers and Service Providers.

- ▶ **Spring 2017**
 - ▶ Mailed out surveys.
 - ▶ Required intense collaborative effort between agencies and volunteers to mail out over 6,000 surveys.
- ▶ **Challenges and Lessons Learned**
 - ▶ Translation and Large Print
 - ▶ Need to inform caregivers about survey before they receive the survey.
 - ▶ **Caregivers did not identify themselves as caregivers.**
 - ▶ **Low Response Rate & Strategy**
 - ▶ Calls to improve response rate: DFTA CG programs and DFTA Research staff & Interns.
 - ▶ Distributed survey to grandparents at GRC support groups and events to improve response rate.
 - ▶ Reminder postcards to complete survey online or by hardcopy.

Process
Stage 3: Analyze Results.

- ▶ **Summer 2017**
 - ▶ **Timeline Challenges:**
 - ▶ Surveys to be completed by July 1st.
 - ▶ Data entry and analysis by August 30th.
 - ▶ Review of data and Recommendations development also to be completed.
 - ▶ Decision was made to extend deadline in order to survey AARP members.
 - ▶ In August 2017 survey was sent to AARP members.
 - ▶ Final report submitted September 30th 2017.
 - ▶ Simultaneous meetings with stakeholder and council members to inform on progress and preliminary results.

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Key Findings - All Caregiver Groups

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

Key Findings - All Caregiver Groups

As a result, the recommendations were responsive to these **core needs**:

- ▶ **Information Gaps:** Caregivers often don't know where to find available services.
- ▶ **Financial and Employment Stability:** Caregivers often have to forego wages or advances in employment.
- ▶ **Enhance Existing Services:** Caregivers need a break.

Demographics: Caregivers of Older Adults

Demographic Breakdown of Older Adults		Caregivers served by ASST	Caregivers not served by ASST
Gender	Male	21%	40%
	Female	79%	60%
	English	90%	93%
Primary language	Spanish	10%	6%
	Other language	4%	4%
Age	Under 35 years	21%	23%
	35 to 64 years	22%	28%
	65 to 74 years	36%	32%
	75 or above years	20%	17%
Race/ethnicity	Hispanic	31%	13%
	White non-Hispanic	30%	51%
	Black non-Hispanic	31%	37%
	Other groups	11%	10%

Percentages could equal more than 100%.
 Note: Percentages for each service are based on unweighted counts of caregivers, according to the questions reported in the table.
 Source: Family Caregiving for Older Adults 2017.

Demographics: Kinship Caregivers

Demographic Breakdown of Kinship Caregivers		ASST Kinship caregivers	ASST Kinship caregivers not served by ASST
Gender	Male	14%	10%
	Female	86%	90%
	English	84%	74%
Primary language	Spanish	18%	24%
	Other language	8%	1%
Age	Under 35 years	11%	40%
	35 to 64 years	27%	34%
	65 to 74 years	40%	21%
	75 or above years	22%	5%
Race/ethnicity	Hispanic	24%	28%
	Black non-Hispanic	83%	27%
	White non-Hispanic	26%	73%

Note: Kinship includes African American caregivers, due to small numbers of caregivers in the non-kinship group.
 Note: Percentages do not equal 100% because of rounding error or multiple responses.
 Source: See report on Family Caregiving for Adults Under 75, 2017.

Demographics: Caregivers of Adults with Disabilities

Demographics		Caregivers of Adults with Disabilities
Gender	Male	14%
	Female	86%
	English	93%
Primary language	Spanish	8%
	Other language	-
Age	Under 30 years	23%
	30 to 59 years	38%
	60 or above years	34%
Race/ethnicity	Hispanic	22%
	White non-Hispanic	40%
	Black non-Hispanic	23%
	Other non-Hispanic	12%

Note: See 5 pages.
 Disabilities could report more than one response. Percentages may not equal 100% because of multiple responses.
 Source: Family Caregiving for Adults with Disabilities 2017.

Financial and Employment Stability

	CG of Older Adults	AARP CG of Older Adults	GRC Kinship Caregivers	ACS Kinship Caregivers	CG of Adults with Disabilities
Cannot Make Ends Meet/Struggle to get by	51%	47%	71%	33%	48%
Employed FT	31%	31%	9%	38%	40%
Employed PT	13%	17%	8%	18%	23%
Affected job	87%	71%	71%	60%	75%



- ### Guiding Principles
- LL97: Recommendation Topics Outlined
1. How to increase information and outreach to unpaid caregivers.
 2. How to expand education and training for unpaid caregivers.
 3. How to educate and involve businesses in addressing workplace issues impacting unpaid caregivers.
 4. How to address issues and concerns with existing programs and services identified through the survey.
 5. Any additional programs and services that may be established to provide support to unpaid caregivers.
 6. How to increase civic engagement and volunteer opportunities to support unpaid caregivers.
 7. Any other issues that the department deems appropriate.

All recommendations were developed to be:

- ▶ **Responsive** to the expressed needs of NYC's unpaid caregivers.
- ▶ **Collaborative**, connecting City services with those on the State and Federal levels.
- ▶ **Pragmatic**, ensuring we can achieve our goals with the tools we have.
- ▶ **Stabilizing**, providing long-term stability for families.
- ▶ **Compassionate** toward the realities caregivers face.

Four Subcommittee Workgroups

- ◆ **Partners:** DFTA, ACS, Ops, OMB, City/State Legislative Affairs, MOPD, DOE, H+H, CGE, THRIVE, AARP, OPWDD
- ◆ **Policy**
Using levers the City has at its disposal to make changes to positively affect the lives of caregivers
- ◆ **Economic Stability (Finance)**
Creating stability in the lives of by enacting or supporting fiscal and labor practices
- ◆ **Services**
Identifying existing services and what potential gaps new services would fill
- ◆ **Communications**
How unpaid caregivers interact with NYC, and how they might better access and become informed about the City's services.


Where we are today

- ▶ Created a Citywide Communications Strategy
- ▶ Educate individual so they can self-identify as a caregiver
- ▶ Call to Action: Let them know there is help and there are services.
- ▶ Develop multi-platform, multimedia campaign
 - ▶ Meet people where they are - how can these audiences best be reached?
 - ▶ Re-Design of a caregiver website
- ▶ Help people navigate the system
- ▶ Additional funding of \$4M baselined received from City Hall for respite and supplemental services.
 - ▶ Targeting working caregivers.
 - ▶ Implementation of increased funding.



**You care for him
We'll care for you.**

Complete a 20-minute assessment of health concerns. Get guidance and support for the best care options for your loved one. Call 800-955-2637 for the "caregiving support."





**She depends on you.
You can depend on us.**

Complete an 8-minute assessment of health concerns, caregiver and patient. Get guidance and support for the best care options for your loved one. Call 800-955-2637 for the "caregiving support."