

A Survey of Informal Caregivers in New York City

2017

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Background & Purpose of the Study

On August 31, 2016, Mayor de Blasio signed **Local Law 97 of 2016**, which requires the New York City Department for the Aging (DFTA) to develop and conduct a survey of unpaid caregivers. The law also requires DFTA to create a comprehensive plan that addresses the needs of unpaid caregivers and to report on the plan's progress after two years and every five years thereafter. The purpose of the legislation is to shine a light on the essential, often invisible, role unpaid caregivers play in the lives of others, to identify ways to strengthen existing services, and to develop new policies and programs to support them.

This study is the first of its kind to examine the extent to which unpaid caregivers' needs are met in NYC and to identify areas for further improvement. The study was created to provide actionable and policy-relevant data on the extent to which unpaid caregivers in New York City obtain the services they need and the barriers they may face in obtaining those services. The study was designed by DFTA and the Mayor's Office for Economic Opportunity (NYC Opportunity) with input from the Administration for Children's Services (ACS), the Mayor's Office for People with Disabilities (MOPD), and community stakeholders including AARP. Conducted by NYC Opportunity in partnership with Westat, a research and statistical analytics firm, the study includes separate surveys for three groups of unpaid caregivers and providers of services to these caregivers.

The three groups are:

- Adults caring for family member(s) aged 60 or over, including adults with Alzheimer's disease or other dementia;
- Grandparents or other older relatives who are the primary caregivers of children under 18; and
- Adults caring for individuals with disabilities between the ages of 18 and 59.

Unpaid family caregiving accounts for the lion's share of long-term services and supports for care of the elderly, kinship care of minors, and care of adults with disabilities. Studies examining the burden and impact of such care on the caregivers' health and well-being have documented the need for greater access to relevant and affordable services such as respite care, case management, legal services, and counseling and mental health supports.

The surveys in this study collectively addressed two broad research questions: **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?**

Specifically, the study addresses the following sub-questions in order to answer the broader research questions:

- What are the demographic profiles of New York City caregivers of older adults, kinship caregivers of minors, and caregivers of adults with disabilities? What are their resources for providing care and burden of care? What is the profile of care recipients?
- What services do family caregivers need for themselves and their care recipients?
- To what extent are the caregivers' needs for services met and what are the levels of unmet need?
- What barriers do caregivers face in obtaining the services they need?
- How do various caregiver groups differ in obtaining the services needed and their levels of unmet need?

In consultation with relevant City agencies and external stakeholders, DFTA will use the study findings to develop a comprehensive plan to address the needs of unpaid caregivers in New York City.

Executive Summary

There are an estimated 900,000 to 1.3 million unpaid caregivers in New York City.² While the three types of caregivers surveyed may not be representative of this entire population, the findings reveal that of all caregivers who completed the survey, most are women and many are seniors. A majority provide at least 30 hours of care per week, with many spending 40 or more hours a week providing care. Many have jobs, and it is not uncommon for these caregivers to encounter problems at work, change to part-time work, or quit their job because of their caregiving responsibilities. Many struggle financially, either barely managing to get by or not able to make ends meet. Caregivers acknowledge needing services like respite care and legal help, but sometimes they do not know that such services are available.

Some of the survey highlights are as follows:

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 services with the highest levels of unmet need** was **respite care—at least 1 in 4** caregivers from each group **need but do not receive it**
- Two of the **most prevalent barriers to obtaining services** are **lack of knowledge regarding available services** and **income/financial limitations**

Caregivers of Older Adults

- Over **three-quarters** were **55 or older**
- About **half cannot make ends meet** or **barely manage to get by**
- **Less than half** are **employed**
- Of those employed, **more than two-thirds say caregiving affected their job**
- About **two in five** spend **40 or more hours** a week **providing care**

Kinship Caregivers

- About **three in four foster care kinship caregivers** (ACS caregivers) are **under 65** years old, while **nearly two-thirds of non-foster care kinship caregivers** (GRC caregivers)³ are 65 or older
- **One-third** of ACS caregivers say they **cannot make ends meet or barely manage to get by**, a statistic that jumps to about **7 in 10** for GRC caregivers
- A **majority** of ACS caregivers **work**, while nearly **three-quarters** of GRC caregivers are **retired**
- A **majority** of employed kinship caregivers **say caregiving affected their job**
- A **majority** of kinship caregivers **provide at least 40 hours of care** each week

Caregivers of Adults with Disabilities

- About **two-thirds** are at least **50 years old**
- A **majority** are **employed** either full-time or part-time
- Of those employed, **three in four** say **caregiving affected their job**
- About **half** say they **cannot make ends meet or barely manage to get by**
- About **two in five** spend at least **40 hours** a week **providing care**

Challenges and Barriers

Who are Unpaid Caregivers

Unpaid caregivers, often referred to as family caregivers or informal caregivers, provide crucial care to people of all ages.⁴ They are adult children whose assistance can range from preparing meals to bathing their elderly parents who are unable to perform these activities of daily living themselves. They are partners and spouses who remind their loved ones with Alzheimer's to take their medicine and pay bills. They are grandparents who raise their young grandchildren, dropping them off at school and picking them up at the end of the day. They are parents of adult children with disabilities who take their care receivers to doctor appointments.

For many, caregiving is a labor of love. But it can also be exhausting, stressful, and overwhelming. While there is no price tag on their work, caregivers often pay a price themselves. Caregiving can take a toll on people physically, emotionally, and financially. For an adult child who is constantly attending to the needs of a parent with dementia, it can mean hours of lost sleep, absence from work, and reduced workplace productivity. For a grandparent with limited physical mobility, a simple task like picking up a child's toys can mean living with more pain. For a single parent with a full-time job, it can mean having to choose between a paycheck and caring for an adult child with a disability.

While the onus placed on caregivers cuts across gender, ethnic, racial, and socioeconomic lines, women are more likely to take on caregiving responsibilities.⁵ Informal caregiving also has a large impact on seniors: in New York State, 85 percent of those receiving caregiver assistance are at least 75 years old, and nearly 25 percent of caregivers are also at least 75 years old.⁶

This report aims to highlight the important and necessary assistance unpaid caregivers provide—whether for a parent, a spouse, a young child, or a family member with a disability—in an effort to improve the quality of life for caregivers and the quality of care for those they help.

A \$470 Billion Industry and a Financial Toll

Across the United States, the economic value of the work family caregivers perform is estimated at \$470 billion a year.⁷ And the economic impact of unpaid caregiving on the families who both require and deliver these services is enormous. The burden takes its greatest toll on those with limited financial resources who inevitably face a daunting choice: either a cut to their paycheck because a family member needs their help or not providing adequate care for their family member. Moreover, the financial strain posed by caregiving responsibilities may extend beyond lost wages. Often, caregivers must pay out of pocket for caregiving expenses such as transportation to the doctor, overnight help, and home modifications like grab bars, walk-in bathtubs, and chair lifts. One study found that caregivers pay an average of nearly \$7,000 a year on caregiving expenses, and these out-of-pocket expenditures represent on average 20 percent of their incomes.⁸

Some caregivers opt to leave the workforce early so that they can provide full-time care to a family member. Those who do so to care for a parent lose on average \$304,000 in wages and benefits over the course of their lives.⁹ There is also evidence suggesting that women who take on a caregiving role in middle age are more likely to live in poverty in old age.¹⁰

Unemployed caregivers are also familiar with the financial hardships that come with caring for someone. Many grandparents raising grandchildren, for example, are retired and live on fixed incomes, leaving them with little or no wiggle room to afford even basic necessities for the child in their care.

Challenges and Barriers, continued

Challenges and Protections in the Workplace

The circumstances caregivers must confront also make them vulnerable to discrimination in the workplace. This unfair treatment might result from situations an employer deems “inconvenient,” like an employee leaving work early to take their adult child to the doctor, taking a day off because a home care worker fails to show up, or leaving work in the middle of the day after getting an unexpected call from their parent who has fallen and needs help.

In January 2016, Mayor Bill de Blasio signed legislation expanding the New York City Human Rights Law to include “caregiver status” as a protected category in employment. This addition will help protect employees with caregiving responsibilities from being terminated, demoted, or denied a promotion.

Differing Perspectives on Caregiving

Whether employed or unemployed, caregivers face more than economic hurdles. Some caregivers, including parents and grandparents, do not recognize themselves as caregivers and thus never avail themselves of benefits and services they need. In certain cases, cultural differences may influence attitudes toward caregiving. Some families, for example, might consider looking after an elderly parent or relative a familial obligation, tradition, or even expectation. This could mean they are unwilling to seek out or accept help or feel ashamed for doing so. In some communities, fear of being judged for placing a family member in a nursing home might make families more likely to rely on each other for care. Sometimes family caregiving arrangements can fuel frustration or even resentment. This can occur when one family member, often a sibling, is forced to shoulder the caregiving burden on their own, without the contribution of other siblings or family members.

Physical and Emotional Toll of Caregiving

Without sufficient support or awareness of the support that is available to them, caregivers face potentially significant financial burdens as well as physical and emotional challenges. Many caregivers, for example, neglect their own health needs to look out for someone else’s. Others must deal with the depression and anxiety that ensue not only from facing the unfortunate conditions of their loved ones, but also from having to juggle the care of their loved ones with their own needs.

In general, caregivers experience higher levels of depression and stress than non-caregivers.¹¹ Caregiving can contribute to loss of self-identity and self-esteem, and can cause exhaustion and feelings of helplessness.¹² Acting as a caregiver can also have serious effects on one’s physical health, including higher risk of heart disease and obesity.¹³ Because of the intensity and longevity of the care they provide, caregivers often miss doctor appointments, eat less healthily, and do not exercise often.¹⁴ And some research suggests that stress caused by caregiving is linked to a higher risk of mortality.¹⁵

Testimony Highlights Challenges of Unpaid Caregiving

A joint hearing for the proposed legislation held on April 11, 2016 by the New York City Council Committee on Aging and Committee on Civil Service and Labor highlighted some of the challenges caregivers face and the support they need.

In written testimony, Marlene Champion, a working nanny who also cares for her grandson with spinal cord injuries sustained in a motor vehicle accident, wrote that “family caregivers like myself who suddenly find themselves in this position need support that [helps] us provide the best care possible for our loved ones and

Challenges and Barriers, continued

also for ourselves.” She also noted that the money required to support her grandson makes it hard to save for retirement and her own care as she grows older.

Barbara Bruce’s testimony revealed her own struggle to balance her paid job as a nanny with her role as a caregiver to her autistic 19-year-old son. “I do wish I had more time and support as a family caregiver,” she wrote.

Jed Levine, Executive Vice President and Director of Programs and Services at CaringKind, cited the case of an elderly man whose wife with Alzheimer’s disease wakes him up every night because she fears that a man she does not know is in her bed. He leaves the apartment, waits, and reenters pretending he has just come home from work to put her at ease.

“You end up sacrificing everything to be there for someone else,” testified Teri Graham, who acted as her mother’s caregiver for three years. “My days extended from sun up to sun down. I couldn’t sleep or eat or even shower. Once I was very sick but couldn’t stay in bed to take care of myself because there wasn’t anyone available to take care of my mother. It became impossible to plan anything because I never knew what curve ball she would throw me or more accurately the dementia would throw me. The stress became unbearable and resulted in headaches, backaches, nervous stomach, high blood pressure and my drug of choice binge eating...It wasn’t fair to ask me to sacrifice my life, plans and job to stay home tied to my mother 24/7.”

Caregiving as Fulfilling

The work of unpaid caregivers is often thankless, but it may also be fulfilling. Grandparent caregivers, for example, can reap benefits like reduced anxiety and a renewed sense of purpose.¹⁶ Despite facing financial and mental health challenges, parents caring for children with autism spectrum disorders can find their caregiving experience fulfilling.¹⁷ Caring for a parent with a neurodegenerative disease like Alzheimer’s or Parkinson’s can help forge stronger bonds between a parent and their adult child caregiver and make adult children appreciative of the opportunity to reciprocate, positive aspects that are associated with a less stressful and overwhelming caregiving experience.¹⁸

Fewer Caregivers for a Growing Senior Population

A 2016 U.S. Census Bureau/National Institutes of Health report projects that the population of Americans 65 and up will almost double to 88 million by 2050.¹⁹ In New York City, the population of adults 60 and older is projected to increase to 1.86 million by 2040, nearly 50 percent larger than what it was in 2000.²⁰ But as the senior population grows, there will be fewer available family caregivers for a growing number of Baby Boomers who will require care. In 2010 the ratio of available caregivers to elderly people in need of care was 7-to-1 and by 2030 is expected to fall to 4-to-1.²¹ As the need for caregivers grows, the need to support caregivers will become even more urgent.

Challenges and Barriers, continued

The home care workforce, comprising personal care aides, home health aides, and nursing assistants, more than doubled in size from 2005 to 2015²² and may contribute to bridging the gap between a shrinking pool of family caregivers and a growing number of people who need their care. Despite difficulties in the home care workforce that include high turnover rates and low wages, home care is one of the nation's fastest growing occupations and is expected to lead all other occupations in job creation from 2014 to 2024.²³

The number of grandparents raising their grandchildren is also growing. In the United States, from 2005 to 2015, the number of children with grandparents as their primary caregivers increased from 2.5 million to 2.9 million.²⁴ This trend can be attributed to a variety of factors including the opioid epidemic, economic hardship, incarceration, military deployment, and physical and mental illness.

An Economic Imperative

Supporting caregivers not only helps keep families together—it is fiscally responsible. When individuals look after family members and loved ones at home, they are providing economic benefits to the state and the City, sparing them the cost of nursing homes and other long-term facilities often borne by taxpayer-funded programs like Medicaid. It is estimated that the voluntary assistance provided by family members saves New York State about \$32 billion annually.²⁵ Grandparent and other relative caregivers play an important role in preventing children from entering the foster care system, and in doing so save U.S. taxpayers more than \$4 billion.²⁶ Research also suggests supporting family caregivers may mean fewer emergency room visits and shorter hospital stays.²⁷

Existing Caregiver Supports

The Older Americans Act and the National Family Caregiver Support Program

While there is no comprehensive Federal, New York State, or New York City plan to support the needs of unpaid caregivers, a variety of services and resources for caregivers do exist.

The Older Americans Act, signed into law by President Lyndon Johnson in 1965, sowed the seeds of the first national effort to support unpaid caregivers. In 2000, the Act was amended to establish the National Family Caregiver Support Program (NFCSP), which provides money to states for services that make it easier for family caregivers to look after their loved ones in their homes. Funding is funneled to local Area Agencies on Aging (AAA), many of which contract with community organizations to provide the services required by law. The resources for caregivers available through the program include information about available services, assistance identifying eligibility and applying for government benefits, individual counseling and support groups, training, respite care, and supplemental services like health supplies and assistive devices.

When the NFCSP was enacted, eligibility for services was limited to family members caring for adults ages 60 and up and grandparents and older relatives acting as primary caregivers of children ages 18 and younger. The 2006 reauthorization of the Older Americans Act expanded the definition of those who may be served through NFCSP to younger grandparents (ages 55 and older), older adults caring for children of any age with a disability, and family caregivers of individuals of any age with Alzheimer's disease or related neurological disorders.

In New York State, NFCSP funding granted to the New York State Office for the Aging is distributed to local AAAs, including DFTA. DFTA in turn currently contracts with nine community organizations to provide services throughout the five boroughs. In Fiscal Year 2017, DFTA received \$3.5 million of federal funding for caregiver support through the NFCSP.

State Efforts

In recent years, New York State has made other investments in caregiver support. In 2015, as part of the State's Alzheimer's Caregiver Support Initiative, Governor Andrew Cuomo allocated \$67.5 million to directly support family caregivers of people with Alzheimer's and other dementias, with funding awarded to nine organizations, including three in New York City.²⁸ Also in 2015, Governor Cuomo signed the New York State Caregiver Advise, Record and Enable Act, which requires hospital workers to train caregivers to perform tasks that the patient will require at home before he or she is discharged.

The statewide initiative NY Connects offers information and assistance on medical and nonmedical long-term services and supports to individuals regardless of their age, disability, diagnosis, income level, or insurance. In New York City, caregivers can get help locating the right resources for themselves and their family members by calling 311 and asking for one of the NY Connects providers located in each of the five boroughs.

Existing New York City Resources for Unpaid Caregivers

In New York City, DFTA operates the Caregiver Resource Center (CRC) and the Grandparent Resource Center (GRC). The CRC is staffed by social workers who provide informational support and referrals to community-based programs and services to caregivers of older New Yorkers. The CRC also provides case consultations to assist community professionals seeking guidance on their client work and engages in public education and outreach to caregivers, professionals, seniors, and the community at large on a range of long-term care issues and supports including Alzheimer's disease, residential alternatives, nursing home placement, caregiving, and senior safety. In addition, the CRC maintains a relationship with the NYPD Missing Persons Unit, enabling CRC

Existing Caregiver Supports, continued

social workers to receive information about Silver Alert notifications, reach out to the family caregivers of the individuals reported missing, and connect them to the right services.

DFTA's GRC provides support to older adult caregivers raising their grandchildren. It empowers grandparents caring for young children by providing training, as well as recreational opportunities and health education. It also conducts targeted outreach to specific communities, including to grandparents and elderly caregivers of children who live in NYCHA developments. In partnership with Cornell University Cooperative Extension NYC, the Center has also offered a "Parenting the Second Time Around" program, which helps grandparents and other relatives providing care strengthen their parenting skills.

The Administration for Children's Services (ACS) offers additional resources for grandparent and other relative caregivers. After a child's initial placement in foster care, ACS facilitates immediate arrangements and necessary referrals to ensure a smooth transition for the child and foster family. These immediate needs range from childcare and school placement to coordination of parental visitation. During subsequent meetings with the child and foster family, ACS works to identify further service needs, making referrals to medical and mental health service providers, connecting families to training opportunities, and providing information about how to obtain other available services. On a case-by-case basis, ACS may also offer special supports to foster parents such as respite care, home health aide services, foster parent support groups, emergency on-call support, safety planning, and connections to community-based supports and trainings.

Recognizing that children placed with kin have greater placement stability and better outcomes, ACS has made placement with kin a top priority in its Foster Care Strategic Blueprint. Kinship care creates the possibility of permanency through the Kinship Guardianship Assistance Program (KinGAP) and improves parent-child and sibling visitation rates, which in turn improves permanency and wellbeing. Every year since 2013, there has been a steady increase in the number of children exiting foster care and achieving permanency through kinship guardianship. From Fiscal Year 2015 to Fiscal Year 2016, ACS increased the number of children achieving permanency through kinship guardianship by 25 percent.

The Mayor's Office for People with Disabilities (MOPD) provides information and referrals to programs for people with disabilities and their family members. City agencies also have designated Disability Service Facilitators (DSFs), who help people with disabilities and their caregivers navigate the programs and services offered at their respective agencies, as well as other relevant City- and State-funded programs.

NYC Well, New York City's free and confidential mental health support hotline, is another resource for caregivers. It allows anyone to connect with a trained mental health counselor via phone, text message, or online chat and is available in over 200 languages.

Nonprofits play a crucial role in supporting caregivers, with a majority of DFTA-funded services provided through contracts with community-based organizations. Caregiver programs provided by these organizations offer information and referrals, counseling, support groups, training, and respite services that include home care, adult day services, and overnight institutional care. They also offer a range of supplemental services that vary from program to program, but may include home cleaning, legal and immigration assistance, telephone reassurance, medication reimbursement, shopping assistance, home modifications, and transportation.

Organizations like the Alzheimer's Association and CaringKind have their own 24/7 Helplines where caregivers of persons with Alzheimer's disease or other cognitive impairment can seek assistance. CaringKind also provides access to the MedicAlert NYC Wanderer's Safety Program, while the Alzheimer's Association offers Safe Return. Both are nationwide identification services that activate an emergency response if needed for an individual with Alzheimer's or related dementia.

Existing Caregiver Supports, continued

Indirect Support for Caregivers

Services directly benefiting care recipients can also greatly benefit their caregivers. Medicare and Medicaid are lifelines for elderly, disabled, and low-income Americans, providing them with vital health care and home health services that make it easier for people to care for their loved ones at home. In addition, home-delivered meal programs provide a service that eliminates both an expense and time-requiring activity for caregivers. Friendly visiting programs give caregivers the opportunity to take a short break while a volunteer keeps their loved one company in the comfort of the home, while social adult day services and senior centers offer caregivers a longer respite, allowing them to go to work or run errands while knowing their loved one is in a safe and engaging environment. Other resources like the Expanded In-home Services for the Elderly Program (EISEP) help reduce expenses by covering part or all of the costs of non-medical services like light housekeeping and grocery shopping. Home delivered meals and EISEP homemaker can be accessed through the network of DFTA-funded case management agencies. Free legal assistance can help seniors at risk of eviction stay in their homes, while the Bill Payer Program trains volunteers to help seniors manage and pay their bills.

Financial Support for Caregivers

While most of the services available to caregivers are educational in nature or aimed at alleviating the physical and emotional burdens of caregiving, there are few programs that compensate caregivers directly for their voluntary service. At the federal level, the Department of Veterans Affairs recognizes the value of compensating caregivers. In 2010, President Barack Obama signed legislation establishing the Program of Comprehensive Assistance for Family Caregivers, which provides caregivers of veterans injured in the line of duty on or after 9/11 with a monthly stipend, as well as travel expenses, health insurance, mental health services, and respite care. There is legislation pending that would extend these benefits to all veterans who have sustained injuries during their service.

In New York State, Medicaid's Consumer Directed Personal Assistance Program is a long-term care service model that allows the consumer or consumer's representative the flexibility to hire, train, supervise, and schedule their own personal assistants to provide care. The personal assistant can be a family member who is not legally responsible for the consumer or the directing representative for the consumer. In addition, a spouse or legally responsible parent cannot be the paid caregiver. Family members who are eligible to be the care recipient's paid personal assistant may have other employment.

Grandparent and other relative caregivers can become kinship foster parents and receive financial support for the cost of caring for a child. Kinship foster homes are approved according to the same standards as non-relative foster homes. In addition, the Kinship Guardianship Assistance Program (KinGAP)

Mr. H, 57

Mr. H cares for his mother, who has heart failure. She also has dementia, once burning a meal on the stove because she forgot that she was cooking.

Ten years ago, he quit his job as an engineer to care for her full-time and has not taken a vacation since. Today he keeps track of her weight, blood pressure, body temperature, and glucose level, making sure she is eating the right foods and taking her medications. He is physically and mentally exhausted, but his mother needs him.

"Time," he says, "is a precious commodity," and he is keenly aware of the social and financial sacrifices that he has had to make as a full-time caregiver. Without income, it is hard to make ends meet. While SNAP helps with the cost of food and Medicare provides temporary home health aide services, it is a constant balancing act.

PSS Circle of Care, he says, is a lifeline. They provide diaper support that helps with the budget and respite care that allows him to do simple things like grocery shopping and going to the doctor. "Without them," he says, "I wouldn't have lasted this long."

Existing Caregiver Supports, continued

helps facilitate the permanent placement of foster children with relatives who have been a child's foster parent for at least six months. Kinship guardians receive financial support similar to the payments they received as kinship foster parents, and in most cases KinGAP covers the child's medical coverage.

Through the Human Resources Administration's job centers, kinship caregivers who are not foster care parents have the right to apply for the Non-Parent Caregiver Grant, a financial benefit provided under the Temporary Aid to Needy Families (TANF) program. Cash Assistance (cash and shelter allowance) is available for kinship caregivers even if one does not have legal custody or guardianship of the child.

Other City, State, and National Efforts

Additional support for family caregivers in the form of remuneration for the services they provide is being considered or implemented at the national, state, and local levels.

The Credit for Caring Act, a Congressional bill with bipartisan support, would create a federal tax credit of up to \$3,000 for family members providing long-term care to a loved one.

While this federal legislation is pending, states are stepping up to the plate. In July 2017, Hawaii became the first state to financially compensate family caregivers. The Kupuna Caregivers Act, signed into law by Governor David Ige, will provide family caregivers who work at least 30 hours a week with up to \$70 a day to cover home care expenses. A total of \$600,000²⁹ has been allocated for the first phase of the program.³⁰ This initiative may serve as an important model for other states and municipalities.

In Washington D.C., the Grandparent Caregiver Program offers low-income residents who are raising grandchildren, great grandchildren, great nieces, or great nephews a monthly subsidy to help care for the children living with them.³¹

Historical Timeline of Caregiver Rights

National

- 1965** ● Older Americans Act signed by President Lyndon Johnson; first national effort to support unpaid caregivers.
- 2000** ● Older Americans Act amended to establish the National Family Caregiver Support Program (NFCSP), which provides money to states for services designed to help family caregivers.

State

- 2015** ● As part of the State Alzheimer’s Caregiver Support Initiative, \$67.5 million allocated to directly support family caregivers of people with Alzheimers/other dementias.

New York State Caregiver Advise, Record, and Enable Act; requires hospital workers to train caregivers to perform tasks patient will require at home before they are discharged.

City

- Jan 2016** ● Expanded NYC Human Rights Law to include “caregiver status” as a protected category in employment.
- Mar 2016** ● “An Aging World: 2015” report released by DFTA, projected that the population of Americans aged 65 and up will almost double to 88 million people by 2050.
- Apr 2016** ● City Council hearing for proposed legislation, Local Law 97.
- Aug 2016** ● City Council passes Local Law 97 of 2016, which requires DFTA to develop and conduct a survey of unpaid caregivers, create a comprehensive plan to address unpaid caregivers’ needs, and report on the plan’s progress after two years and every five years thereafter.

Survey Methods

The surveys for caregivers were developed through reviewing the research literature on caregivers and input from experts. Three separate but similar surveys were developed for the different caregiver types (i.e., older adults, adults with disabilities, kinship) and the survey questions covered the following topics: 1) sociodemographic information on both caregivers and their care receivers, 2) types of care provided (e.g., bathing, dressing), 3) services both needed and received, 4) satisfaction with services, 5) barriers to services, and 6) what kind of caregiving help was received from friends and family.

The sampling approach varied based on the caregiver type. A randomized sample was drawn based on individuals who utilized caregiver services via New York City government agencies or community-based organizations in the three years preceding the study, for both caregivers of older adults and caregivers identified through a sample obtained from AARP, as well as caregivers through ACS kinship foster care. Kinship caregivers were also contacted by obtaining a listing of all individuals obtaining services through DFTA's Grandparent Resource Center (GRC) or Community Based Programs. Additionally, a small number of individuals participating in kincare support groups were also invited to complete the survey. Caregivers of individuals with disabilities were invited to participate in the survey through four of the largest agencies serving individuals with physical and/or developmental disabilities in New York City.

Caregivers of older adults were contacted through caregiver programs offered through DFTA and associated community-based organizations. An additional sample of caregivers of older adults included individuals who had reached out to AARP. Caregivers of adults with disabilities were contacted through the New York State Office for People with Developmental Disabilities (OPWDD), the Mayor's Office for People with Disabilities (MOPD), and community-based disability organizations. Kinship caregivers were contacted through DFTA's Grandparent Resource Center (GRC) and the Administration for Children's Services (ACS). A total of 2,107 caregivers completed a survey; 1,091 of them were caregivers of older adults, 506 of them were caregivers of adults with disabilities, and 510 of them were kinship caregivers. The response rates varied from 10 percent for caregivers of older adults and 12 percent for caregivers of adults with disabilities to around 30 percent for kinship caregivers (30 percent for DFTA's GRC caregivers and 31 percent for ACS caregivers).

The survey of providers of services to caregivers (hereafter known as the "provider survey") was also informed by caregiver research literature and input from experts. In addition to including general questions about the providers, the survey was divided into three sections representing each of the caregiver types: 1) caregivers of older adults, 2) caregivers of adults with disabilities, and 3) kinship caregivers. The survey contained questions asking providers about their organizations overall, as well as questions about services for caregivers and care receivers. Of the 75 providers that were sent the survey, 29 (38.7 percent) completed the survey. The response rates varied from 13 percent for kincare providers and 32 percent for providers for individuals with disabilities, to 81 percent for caregiver programs for older adults.

Survey Findings

Caregivers of Older Adults, Kinship Caregivers, and Caregivers of Adults with Disabilities

This section contains selected findings from the surveys of caregivers of older adults, kinship caregivers of minors, and caregivers of adults with disabilities. It provides a snapshot of caregivers’ demographic characteristics, as well as employment levels and financial circumstances. It also offers a look at the different levels of burden among these caregivers, including the amount of personal care they provide and the amount of time they spend caregiving. Finally, it examines the services caregivers and care recipients need and the extent to which their needs are unmet, as well as the barriers caregivers face in obtaining services.

Demographic Profile of Caregivers

Caregivers of Older Adults

Caregivers of older adults served by DFTA and AARP were mostly women, 55 or older, and either White non-Hispanic or Black non-Hispanic.

- Although women accounted for a much larger share than male caregivers of older adults in both groups, the percentage of women caregivers was higher among DFTA caregivers than AARP caregivers (79 percent versus 60 percent).
- Caregivers contacting DFTA were slightly younger than those contacting AARP; 46 percent of DFTA caregivers and 59 percent of AARP caregivers were 65 or over.
- More than two-thirds of the caregivers in both groups were either White Non-Hispanic or Black Non-Hispanic, although White Non-Hispanic caregivers accounted for a much smaller share of the DFTA caregivers (37 versus 51 percent). Hispanic individuals accounted for 21 percent of DFTA caregivers and 13 percent of AARP caregivers.
- Almost all of DFTA and AARP caregivers reported English as their primary language (90 and 92 percent, respectively).



Demographics: Caregivers of Older Adults		Caregivers served by DFTA	Caregivers served by AARP
Gender	Male	21%	40%
	Female	79%	60%
Primary language ¹	English	90%	92%
	Spanish	10%	6%
	Other languages	4%	4%

Demographic Profile of Caregivers, continued

Demographics: Caregivers of Older Adults, continued		Caregivers served by DFTA	Caregivers served by AARP
Age	Under 55 years	21%	13%
	55 to 64 years	32%	28%
	65 to 74 years	26%	32%
	75 or above years	20%	27%
Race/ethnicity	Hispanic	21%	13%
	White non-Hispanic	37%	51%
	Black non-Hispanic	31%	27%
	Other groups	11%	10%

¹ Respondents could report more than one response

Note: Percentages for each service are based on estimated numbers of caregivers responding to the questions reported in this table: (DFTA=9,400; AARP=7,700).

Source: Family Caregiving for Older Adults: 2017.

Ms. C, 75

Ms. C has cared for her husband with dementia for five years. When he first started to show signs of dementia, she did not understand what was happening. “I was lost,” she says. But then she learned of the Alzheimer’s Association, which helped her understand what the disease was, what behaviors to expect, and how to care for someone with it. When her husband shows signs of aggression, she calls the Association’s 24-hour hotline. She knows if she calls someone will listen and walk her through what to do.

Twice a month, Ms. C attends a support group provided through Sunnyside Community Services. She is able to speak openly about her experiences and meet other caregivers whose situations are similar to hers. She says “it’s like therapy” and that when she is there, she doesn’t feel alone.

Demographic Profile of Caregivers, continued

Kinship Caregivers

Kinship caregivers identified by GRC and ACS show some interesting similarities and differences in their demographic composition.

- Both groups of kinship caregivers were overwhelmingly women, accounting for 86 of GRC caregivers and 90 percent of ACS caregivers.
- More than half of the caregivers were Black Non-Hispanic, representing 53 percent of GRC caregivers and 61 percent of ACS caregivers. About one-fourth of GRC and ACS caregivers were Hispanic.
- ACS caregivers were generally younger than GRC caregivers. About three in four ACS caregivers (73 percent) were under 65 years compared with 37 percent of GRC caregivers in this age group.
- Almost all of ACS caregivers reported English as their primary language as did most GRC caregivers (94 and 84 percent, respectively).



Demographics: Kinship Caregivers		GRC kinship caregivers	ACS kinship caregivers
Gender	Male	14%	10%
	Female	86%	90%
Primary language	English	84%	94%
	Spanish	18%	14%
	Other languages	5%	1%
Age	Under 55 years	11%	40%
	55 to 64 years	27%	34%
	65 to 74 years	40%	21%
	75 or above years	23%	5%
Race/ethnicity ¹	Hispanic	24%	28%
	Black non-Hispanic	53%	57%
	Other non-Hispanic ¹	24%	15%

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

Note: Percentages do not sum to 100 because of missing data or multiple responses.

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

Demographic Profile of Caregivers, continued

Caregivers of Adults with Disabilities

Caregivers of adults with disabilities were mostly women and over the age of 50. They were more likely to be White non-Hispanic than other race/ethnic groups

- Most caregivers of individuals with disabilities were women (84 percent) and about two-thirds were 50 years or older (68 percent).
- White non-Hispanic caregivers accounted for 40 percent of the respondents although 23 percent of the caregivers were African American non-Hispanic and 22 percent were Hispanic.
- Almost all caregivers were fluent in English, with 93 percent reporting English as the primary language.



Demographics		Caregivers of Adults with Disabilities
Gender	Male	16%
	Female	84%
Primary language ¹	English	93%
	Spanish	8%
	Other languages	*
Age	Under 50 years	32%
	50 to 59 years	34%
	60 or above years	34%
Race/ethnicity	Hispanic	22%
	White non-Hispanic	40%
	Black non-Hispanic	23%
	Other non-Hispanic	15%

* Less than 1 percent

¹ Respondents could report more than one response. Percentages may not sum to 100 because of multiple responses.

Source: Family Caregiving for Adults with Disabilities: 2017.

Caregiver Employment and Financial Resources

Caregivers of Older Adults

Caregivers served by DFTA and AARP both reported relatively limited employment and financial resources for providing family care to older adults.

- Caregivers of older adults were likely to be unemployed. While 44 percent of DFTA caregivers and 48 percent of AARP caregivers worked either full- or part-time, about half of the caregivers were retired (48 and 47 percent, respectively).
- Caregiving had a slightly more negative impact on employment for AARP caregivers than for DFTA caregivers. Of the caregivers who were employed during the three years preceding the survey, 71 percent of AARP caregivers and 67 percent of DFTA caregivers reported that caregiving negatively affected their job, including having problems at work, changing to part-time work, and quitting jobs.
- When asked about their financial situation, 51 percent of DFTA caregivers and 47 percent of AARP caregivers reported financial struggles. For example, among DFTA caregivers, 44 percent reported they barely managed to get by and 7 percent said they could not make ends meet.

Employment and Financial Resources		Caregivers served by DFTA	Caregivers served by AARP
Employment Status	Employed full time	31%	31%
	Employed part time	13%	17%
	Not employed or looking for work	9%	6%
	Retired	48%	47%
Effect of Caregiving on Employment ¹	Affected employment	67%	71%
	Did not affect employment	34%	29%
Financial Situation	Cannot make ends meet	7%	9%
	Barely manage to get by	44%	38%
	Have enough to manage	44%	47%
	Have more than enough to manage	5%	7%

¹ Percentages are based on caregivers who were employed during the three years preceding the survey.

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

Source: Family Caregiving for Older Adults: 2017.

Caregiver Employment and Financial Resources, continued

Kinship Caregivers

GRC caregivers reported greater financial difficulty than ACS caregivers. This may be explained by the fact that GRC caregivers are mostly retired and likely to live on fixed incomes, while ACS caregivers are more likely to be employed. In addition, the foster care stipend that ACS caregivers typically receive is financially greater than the TANF grant available to GRC caregivers.

- Suggesting limited income resources, about three in four GRC kinship caregivers (73 percent) were currently retired while only 17 percent were employed either full- or part-time. In contrast, more than half of ACS caregivers (56 percent) were employed while 29 percent were retired.³²
- When asked about the impact of caregiving on their employment during the three years preceding the survey, GRC caregivers were more likely than ACS caregivers to report negative effects (71 versus 60 percent). These included having problems at work, changing to part-time work, and quitting jobs.
- Consistent with employment patterns, GRC caregivers were more likely than ACS caregivers to report financial situations in which they barely manage to get by or cannot make ends meet (71 versus 33 percent).

Employment and Financial Resources		GRC kinship caregivers	ACS kinship caregivers
Employment Status	Employed full time	9%	38%
	Employed part time	8%	18%
	Not employed or looking for work	10%	14%
	Retired	73%	29%
Effect of Caregiving on Employment ¹	Affected employment	71%	60%
	Did not affect employment	29%	40%
Financial Situation	Cannot make ends meet	9%	2%
	Barely manage to get by	62%	31%
	Have enough to manage	28%	63%
	Have more than enough to manage	1%	4%

¹ Percentages are based on caregivers who were employed during the three years preceding the survey.

Note: Percentages may not sum to 100 because of rounding.

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

Caregiver Employment and Financial Resources, continued

Caregivers of Adults with Disabilities

Many caregivers of adults with disabilities faced employment and financial challenges while providing family care for the adults with disabilities.

- About two in three caregivers (63 percent) were currently employed, with 40 percent holding full-time jobs and 23 percent having part-time jobs. Only 25 percent of the caregivers were retired.
- Many caregivers (75 percent) experienced a negative impact of caregiving on their jobs in the three years preceding the survey, including situations where they had problems at work, changed to part-time work, or quit their jobs.
- Nearly half of the caregivers (48 percent) reported challenging financial situations; 38 percent could barely manage to get by and 10 percent could not make ends meet.

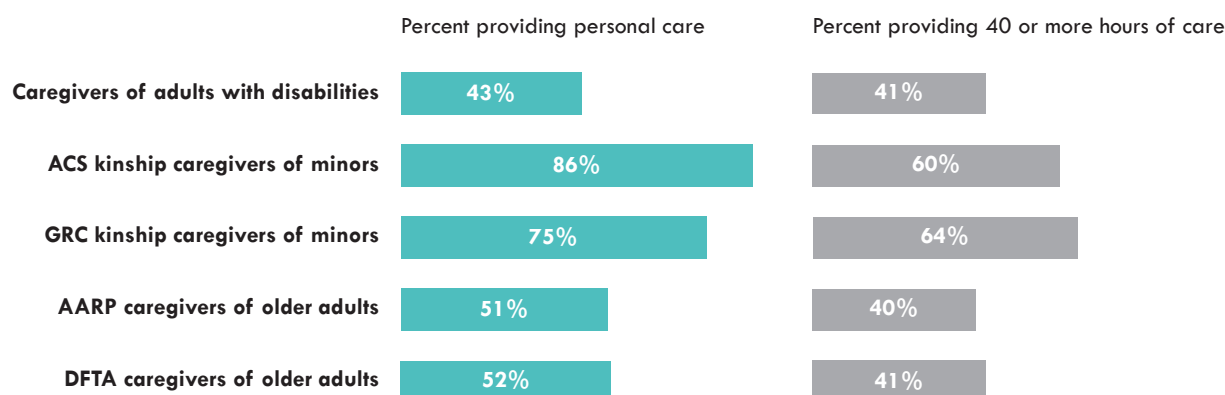
Employment and Financial Resources		Caregivers of Adults with Disabilities
Employment Status	Employed full time	40%
	Employed part time	23%
	Not employed or looking for work	12%
	Retired	25%
Impact of Caregiving on Job ¹	Affected employment	75%
	Did not affect employment	25%
Financial Situation	Cannot make ends meet	10%
	Barely manage to get by	38%
	Have enough to manage	45%
	Have more than enough to manage	7%

¹ Percentages are based on caregivers who were employed during the three years preceding the survey.
Source: Family Caregiving for Adults with Disabilities: 2017.

Caregiving Burden

Two key measures of caregiving burden examined in this study are 1) the type of care provided, and 2) the time spent providing such care. Caregivers' responses to the survey questions about providing personal care and the number of hours spent per week providing care offer important insights into the potential need for support services to help alleviate burden. Figure 1 provides a global view of these two measures of burden across the four groups of family caregivers participating in this study.

Figure 1. Burden of providing care, by caregiver type



The study findings support expectations that kinship caregivers of minors may be highly likely to provide personal care and spend long hours in caregiving since young children are dependent on adults to satisfy basic needs, such as eating and bathing. Most ACS caregivers and three in four GRC caregivers provided personal care to the minors in their care (86 and 75 percent, respectively). They also spent long hours providing care; 60 percent of ACS caregivers and 64 percent of GRC caregivers spent 40 hours or more per week taking care of their minors.

Many caregivers of older adults also provided personal care and spent considerable hours on such care, presumably because older care recipients tend to encounter serious health issues, including memory problems and physical immobility. About half of the DFTA and AARP caregivers of older adults provided personal care (52 and 51 percent, respectively) and about two in five spent 40 hours or more per week on family caregiving (41 and 40 percent, respectively).

Although adults with disabilities face a wide range of physical and developmental or intellectual challenges, the caregivers were the least likely to provide personal care or spend 40 hours or more on family caregiving (43 and 41 percent, respectively).

Caregiving Burden, continued

Differences in human capital resources among caregiver groups provide insights on how caregivers cope with the burden of caregiving as well as their needs for services.

- GRC caregivers were least likely to be employed (17 percent) compared with employed DFTA and AARP older adult caregivers (44 and 48 percent, respectively). More than half of caregivers of adults with disabilities were employed (56 percent) and almost two-thirds of ACS kinship caregivers were employed (63 percent).
- When asked about their financial situation, GRC kinship caregivers were more likely than all other caregivers to report that they barely manage to get by or can barely make ends meet (71 percent) while ACS kinship caregivers were least likely to report such financial challenges (33 percent). About half of AARP caregivers and close to half (47 percent) of DFTA caregivers were employed.

Mr. M, 73

Mr. M has overcome great adversity, raising his grandson while simultaneously battling and surviving cancer himself. He says there were many times he questioned how he was going to make it through the day. But knowing that his grandson would have no one else to care for him, he persevered. Today, his grandson is 12 years old and a kind and thoughtful young man—a model of the man who raised him.

Ms B, 72

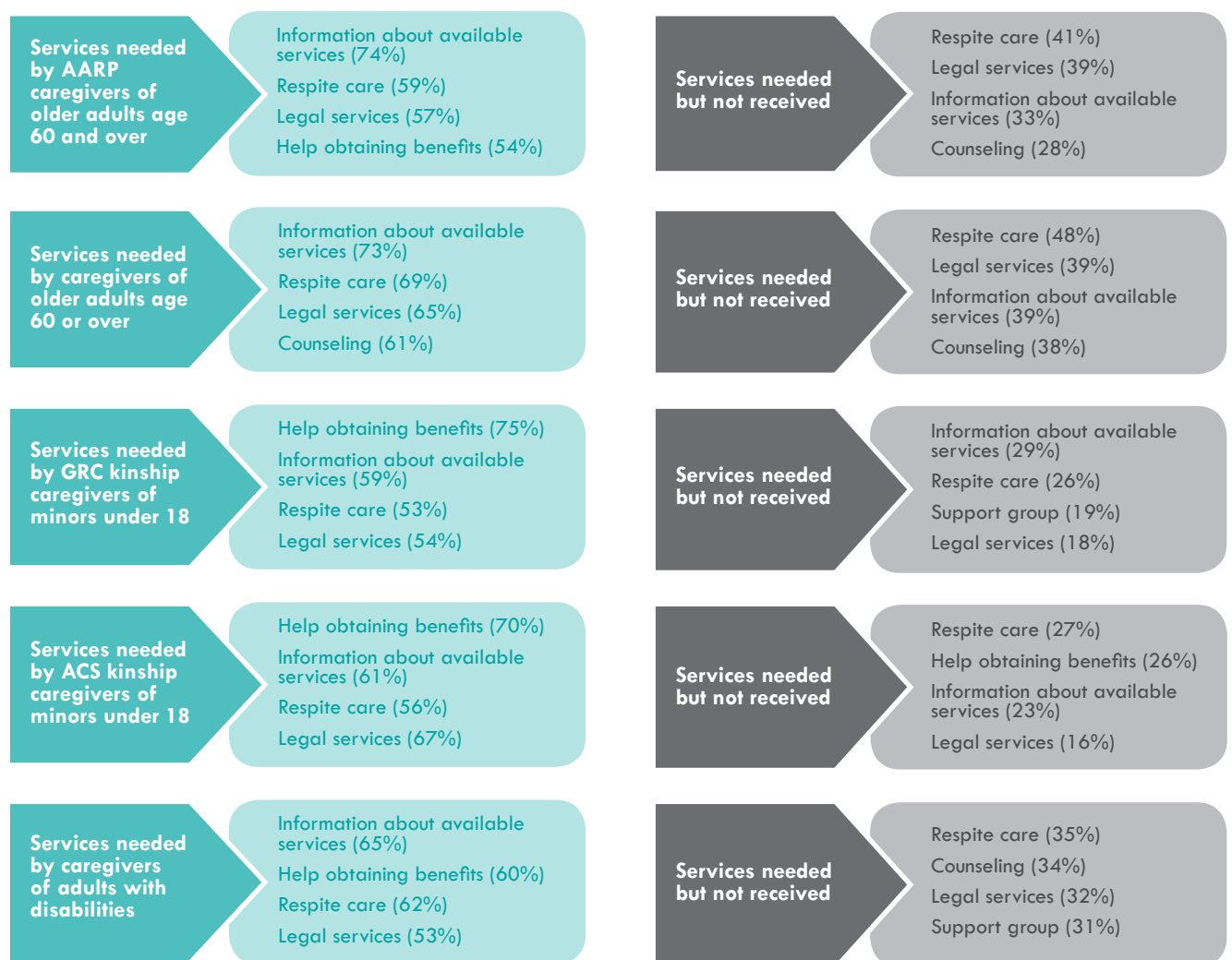
Ms. B is a great-aunt who adopted her then-seven-year-old great-nephew as her son in 2010. Ms. B and her family became involved in the foster care system when her great-nephew was three months old and his biological mother was battling substance abuse. Since the adoption, Ms. B has taken great care to tend to her son's wellbeing while also taking care of other grandchildren in the family; she continues to be respectful of the biological mother's role in her adopted son's life. While Ms. B never expected to adopt her great-nephew, and admits the process to become a kinship caregiver was "messy," she loves her son and is honored to be his mother. She continues to tell other grandparents and kinship caregivers her story and encourages them not to give up. Ms. B has completed the Parenting a Second Time Around (PASTA) program and attends a support group at New Alternatives for Children.

Services Caregivers Need

Figure 2 presents the four services at the top of the lists for what caregivers needed and what they needed but did not receive. Unmet need has important implications for policies aimed at improving services for the various groups of caregivers and their care recipients. Since the list of services is similar for the four caregivers groups, it is possible to examine the overlap in need for services and unmet need across caregiver types. It is also worth noting that when a caregiver receives a service, that does not necessarily mean the caregiver’s needs are being met. For example, if a caregiver needs and receives respite care, the hours or kind of respite care provided might not satisfy the caregiver’s need.

Across caregiver groups, more than half of the caregivers needed three services—information about available services, respite care, and legal services (Figure 2). Other services at the top of the list were counseling for caregivers of older adults, and help obtaining benefits for the four other caregiver groups.

Figure 2. Services at the top of the list for various groups of caregivers



Services Caregivers Need, continued

When the demand for services is examined against the extent to which the needs are unmet, there is considerable overlap, suggesting that the areas of greatest demand may also be the areas with high levels of unmet need for many caregivers. For example, the survey data show that:

- For all caregiver groups, respite care was among the top four services in demand but it was also among the services with high levels of unmet need.
- Other services at the top of the needs list and that had high levels of unmet need were information about services, help obtaining benefits, legal services, and counseling.

Services Care Recipients Need

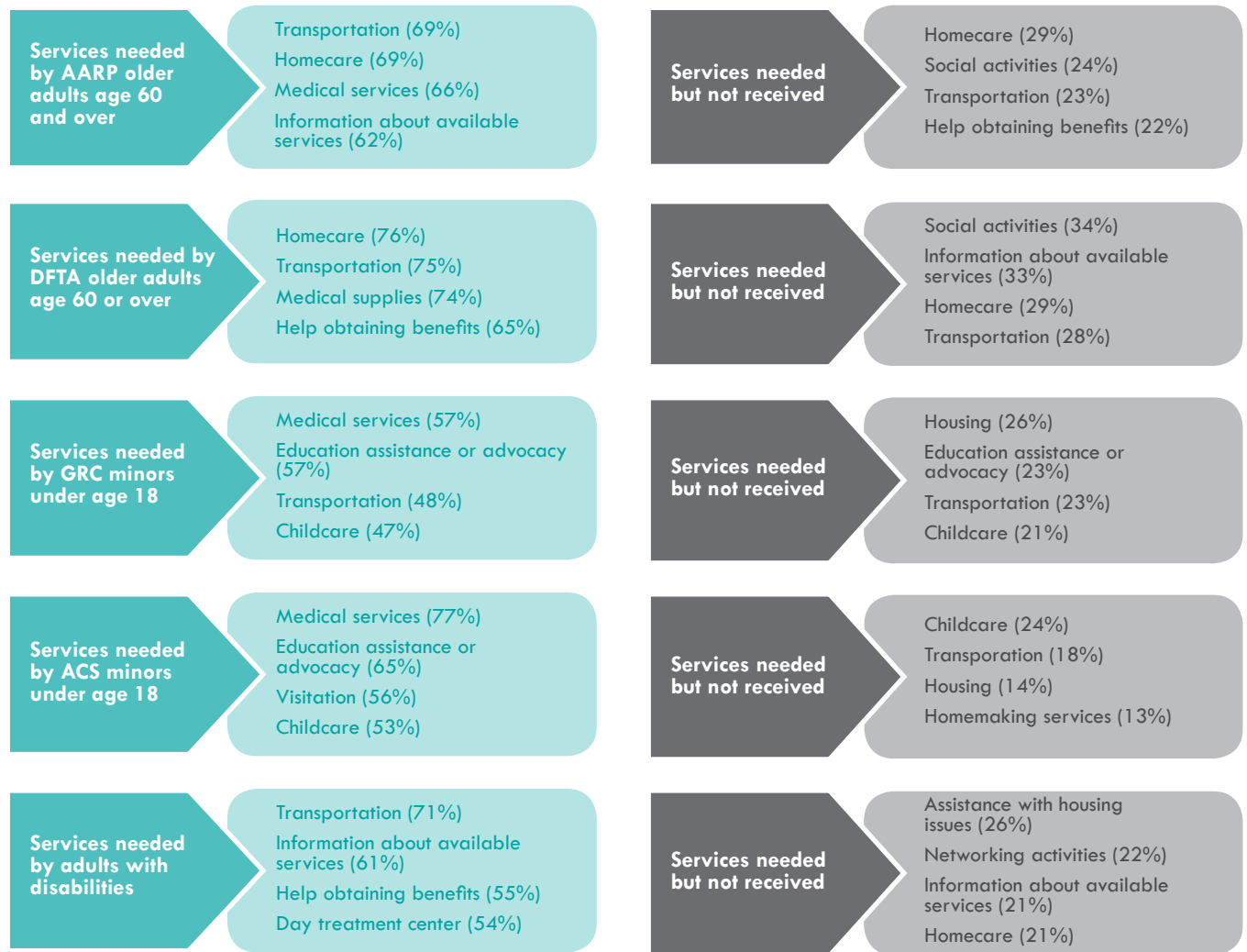
Although there was some overlap, the surveys asked about services that were relevant to each care recipient group—DFTA and AARP care recipients, minors of kinship caregivers, and adults with disabilities. Thus, the demand for each pool of care-recipient services is examined against unmet need both within each of the three groups and across groups where applicable. Unmet care needs among care recipients can increase the burden on caregivers and limit their ability to provide adequate care.

Figure 3 presents the top services for which about half or more of each care recipient needed and the three or four services at the top of the list of services with unmet need.

- While older adults in family care had a high demand for homecare, transportation, and medical supplies, they also had high levels of unmet need in homecare and transportation. Other areas of high unmet need included social activities and information about available services.
- Similar to DFTA older adults, AARP older adults had a high demand for transportation, homecare, and medical information and supplies. They also had high levels of unmet need in homecare and transportation. Other areas of high unmet need include social activities and help obtaining benefits.
- GRC minors in kinship care had a high demand for medical services, education assistance, and transportation. They had high levels of unmet need in medical services, education assistance, and housing.
- Like their GRC counterparts, ACS care recipients had a high demand for medical services and education assistance and high levels of unmet need in this area and in transportation and childcare, presumably because they are more likely to be employed.
- Adults with disabilities had a high demand for transportation and information about available services, but also had a high level of unmet need for information about available services.

Services Care Recipients Needed and Received, continued

Figure 3. Services at the top of the list for various groups of care recipients



Barriers to Obtaining Services

Caregivers were asked about the difficulties they face in obtaining various services for themselves and the people in their care. For each listed service, caregivers indicated whether they experienced each of the listed difficulties. To gather additional information about barriers to services not included in the question, the survey asked caregivers to enter this information in text boxes.³³

Across all services listed in the surveys, and for each of the four groups of caregivers, the most frequently cited difficulty was that caregivers did not know if the service was available. These services included respite care and legal services for caregivers of older adults; housing and counseling for GRC kinship caregivers, and respite and counseling for caregivers of adults with disabilities. Some caregivers also cited financial difficulties in obtaining legal services while some reported wait lists as a difficulty in obtaining housing services.

Barriers to Obtaining Services, continued

For example:

- Among DFTA and AARP caregivers of older adults, many did not know if respite care was available (38 percent and 25 percent, respectively) and reported financial difficulties in obtaining this service (20 percent for both groups). Very few respondents from either group reported difficulties associated with speaking to agency staff in English for any service.
- Among ACS and GRC kinship caregivers, many reported that they did not know whether housing services were available (21 percent and 17 percent, respectively), whether counseling or therapy services were available (13 percent and 18 percent, respectively), or whether legal services were available (12 percent and 16 percent respectively). Financial issues related to legal services were also reported by ACS and GRC caregivers (17 percent and 11 percent, respectively).
- Caregivers for adults with disabilities financial issues in obtaining respite care (13 percent), help obtaining government benefits (12 percent), and counseling/therapy (10 percent).

Based on a review of the caregivers' written responses, the most frequently cited services across caregiver groups were transportation, homecare, government benefits, housing, and respite. For example:

- Transportation was consistently cited as a barrier and source of frustration among caregivers mainly because it was unreliable, time consuming, and inadequate for care recipients, especially for those who use wheelchairs.
- Homecare posed many difficulties for caregivers, including issues with limited hours and nighttime care, eligibility problems, waitlists, quality of care, and lack of training and supervision of aides.
- Government benefits are a critical source of financial support for many caregivers, especially those with low employment and limited financial resources. Caregivers reported difficulties that were mostly related to SNAP, Medicare, Medicaid, and veterans benefits.
- Housing issues included a lack of access or prolonged waitlists for senior housing, rental housing, affordable housing, and relocation, as well as residential alternatives that may include accessible housing and supportive housing for persons with dementia.
- Respite care was consistently cited by caregivers as either inadequate or unavailable. Many caregivers underscored the need for short-term relief from caregiving that was often intense and ongoing for many years. In particular, caregivers needed more respite, in-home and overnight respite, and weekend respite.

Public Awareness of Available Caregiving Services

The survey asked caregivers how they learned about the services received from community organizations or government agencies. Across caregiver groups, the most frequently cited sources of information were word of mouth and referrals from health professionals. For example, close to half (46 percent) of caregivers of older adults reported learning about services through word of mouth and 38 percent cited health professionals as the source of information.

Caregiver Service Providers

The provider survey explores caregiving from the perspectives of the agencies and organizations that provide services for the three types of unpaid caregivers, offering a look at who they serve, what services they provide and their ability to meet demand, and how the caregivers they serve learned about them. While the provider survey respondents do not represent the entire landscape of caregiver service providers, their survey responses offer important context for understanding how caregivers access the services they need and receive.

Overall, the 36 agencies whose caregiver clients participated in the survey serve about 111,000 caregivers and/or their care recipients and are staffed by over 9,000 individuals. Almost all of the agencies (34 of the 36) provide direct services such as support groups, respite care, help with obtaining government benefits, homecare, and housing assistance.

Waitlists

The number of caregivers on waitlists sheds a light on the extent to which agencies are able to meet the demand for services. At the same time, it is worth noting that very few of the surveyed caregivers listed waitlists as a barrier to receiving services. The number of caregivers or care recipients on waitlists varied widely across the range of services examined in the survey.

- Services with the highest numbers of **caregivers of older adults** on waitlists were housing assistance (1,055), in-home respite care (434), mental health treatment (300), assistance with accessing government benefits (215), homecare (203) and socialization activities (200).
- Services with the highest numbers of **kinship caregivers** on waitlists were respite (60), housing assistance (28), assistance with accessing government benefits (19), educational assistance/advocacy (10), and employment services (10).
- Services with the highest numbers of **caregivers of adults with disabilities** on waitlists were homecare (375), in-home respite care (325), educational programming (303), assistance with accessing government benefits (271), transportation services (250), housing assistance (210), mental health treatment (208), and socialization activities (200).

Ms. J, 67

Ms. J cares after a friend of hers who lives in her building. “I try to make sure that he keeps his appointments, and most of the time he can do things and get them done. I still haven’t been able to get him to go to the dentist though,” she says, laughing. Ms. J says she cares for him because they’ve been friends for years—if not her, then who?

Although she’s happy to be there for her friend, Ms. J says she wishes people knew that caregiving was real work. “It’s not all fun and games. It’s not easy,” she says. Ms. J, who is retired, says her saving grace has been a support group for caregivers in her building. They meet twice a month to talk about their experiences and challenges. “It lets you know you’re not the only one that’s got a problem,” she says. “It helps, just like anything, to know other people understand what you’re struggling through.”

Public Awareness about Available Caregiving Services

To examine public awareness of agencies and the services they provide, the survey asked agencies about how the caregivers and/or the care recipients learned about the agency.

- Of the agencies reporting that they served caregivers of older adults, 23 reported that caregivers found out about the agency through word of mouth, 21 reported that caregivers found out about the agency through referrals from healthcare, and 21 reported that caregivers found out about the agency through referrals from social service organizations.
- Of the agencies reporting that they served kinship caregivers of minors, 14 reported that caregivers found out about the agency through 311 referrals, 10 reported that caregivers found out about the agency through social service organizations, 9 reported that caregivers found out about the agency through word of mouth, 8 reported that caregivers found out about the agency through referrals from healthcare professionals, and 8 reported that caregivers found out about the agency through a website, which presumably included Internet searches for services available for caregivers and care recipients and the agencies providing such services.
- Of the agencies reporting that they served caregivers of adults with disabilities, 18 reported that caregivers found out about the agency through referrals from social service organizations, 15 reported that caregivers found out about the agency through word of mouth, 13 reported that caregivers found out about the agency through referrals from healthcare professionals, and 12 reported that caregivers found out about the agency through a website, which presumably includes Internet searches for services available for caregivers and care recipients and the agencies providing such services.

Ms C, 61

Ms. C has cared for her husband with dementia for five years. When he first started to show signs of dementia, she did not understand what was happening. “I was lost,” she says. But then she learned of the Alzheimer’s Association, which helped her understand what the disease was, what behaviors to expect, and how to care for someone with it.

When her husband shows signs of aggression, she calls the Association’s 24-hour hotline. She knows if she calls someone will listen and walk her through what to do.

Twice a month, Ms. C attends a support group provided through Sunnyside Community Services. She is able to speak openly about her experiences and meet other caregivers whose situations are similar to hers. She says “it’s like therapy” and that when she is there, she doesn’t feel alone.

Next Steps

Based on the survey findings, as well as feedback from multiple agencies and input from advocates and stakeholders, the City believes more must be done to serve its large population of unpaid caregivers. New York City has already made significant investments to support caregiver services, and is poised to be a leader in addressing the burdens caregivers face.

The diverse nature of New York City's unpaid caregiver population means that no City agency is wholly tasked with addressing their needs. Conversations with agency partners point to clear ways the City can support these invaluable members of our community. The City will convene a steering committee to review the survey results in detail and make informed recommendations to better serve its unpaid caregivers. The committee will be composed of issue-specific working groups that focus on areas of unmet need identified in the survey findings. It will consist of representatives from DFTA, ACS, MOPD, OMB, and other City agencies, as well as members of the City Council and external stakeholders. The committee will hold its first meeting in Fall 2017, and share recommendations by the end of 2017.

End Notes

1. The full text of the legislation can be found by searching “Int 1081-2016” on the City Council’s legislation search engine at <http://legistar.council.nyc.gov/Legislation.aspx>.
2. The overall caregiver population estimate is based on extrapolating to the 2016 New York City population from a New York City survey done in 1998^a and a more recent national survey.^b

^aLevine, Carol et al. “A Survey of Family Caregivers in New York City: Findings and Implications for the Health Care System” A United Hospital Fund special report, produced in collaboration with the Visiting Nurse Service of New York, 2000.

^bNational Alliance for Caregiving (NAC) and AARP Public Policy Institute. “Caregiving in the U.S.” Research Report, June 2015.
3. Kinship caregivers in the survey sample included two groups: those caring for children in the kinship foster care program administered by ACS; and grandparent and other relative caregivers identified through the DFTA-funded Grandparent Resource Center (GRC).
4. Although family caregivers may receive government assistance for providing care, they are considered unpaid caregivers because they are not paid hourly wages for providing such care.
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End Notes, continued

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33. This additional information is not available for ACS caregivers because the survey did not allow for text responses.