

Sustaining Informal Caregivers

New York State Caregiver Support Programs Participants Survey



Report of Findings on the Aging Services Network 2009

Funded by the Administration on Aging
Performance Outcomes Measures Project

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New York State Office for the Aging (NYSOFA) and Area Agencies on Aging Reviewers

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The survey methodology was developed and directed by I-Hsin Wu, New York State POMP Director, who also prepared the Report.

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Introduction

For more than two decades, the New York State Office for the Aging (NYSOFA) has developed and implemented an array of services that support and assist informal caregivers in caring for their loved ones aged 60 and older who are frail, chronically ill, or in need of assistance in daily tasks.¹ Informal caregivers are generally defined as individuals who provide assistance to someone who has physical or mental impairments and is in need of help with tasks of daily living. These caregivers are usually family members, friends, and neighbors, who are not paid for the support and assistance they provide.

There are some formal services, provided by paid care providers or volunteers associated with a formal service program, available to caregivers and care receivers. The types of caregiver support services provided through NYSOFA and local Area Agencies on Aging (AAAs) include:

- Information about available programs and services;
- Assistance in gaining access to programs and services;
- Services such as individual counseling, support groups, training to assist caregivers in the areas of health, nutrition, financial literacy, and support to make decisions and solve problems related to their caregiving roles;
- Respite care to temporarily relieve caregivers from their responsibilities by providing a short-term break through home care, overnight care in an adult home or nursing home, adult day care and other community-based care; and
- Supplemental services to complement the care provided by the caregiver, such as a personal emergency response system, assistive technology, home modifications, home delivered meals, transportation, etc.

Past NYSOFA/AAA caregiver reports tend to be limited to the number of caregivers and care receivers served by aging services network programs and services, and the units of services utilized, with little information about their detailed demographic characteristics, functional status, health conditions, caregiving experience, and the impact of the services they received. To enhance understanding and provide a clear portrait of caregivers, care receivers, and the impact of aging services, a survey was undertaken in 2008 to: (1) gather detailed information that describes the caregiver population who receive services from NYSOFA/AAA caregiver programs and services; (2) quantify and demonstrate the impacts of NYSOFA/AAA support services and programs on caregivers; and (3) help inform program administrators, service providers, and policy makers so that they may improve programs and services for caregivers.

The Sustaining Informal Caregivers: New York State Caregiver Support Programs Participants Survey Report of Findings on the Aging Services Network that is based on the survey results, underscores the importance of caregivers and their roles in the lives of older adults in communities across New York. It is the first effort to systematically document the impact and

¹ See New York State Caregiver Services Survey: NY Connects Local Long Term Care Councils' Assessment of Caregiver Support Services. Report to the Family Caregiver Council. Caprio, T., Katz, P., Karuza, J., and Rehse, D. (2009).

merit of NYSOFA/AAA caregiver support programs and services in assisting caregivers caring for their loved ones. The Report is divided into eight sections:

- ***Survey Objectives and Methodology:*** This section provides a brief description of the methodology used to collect the survey data.
- ***Caregiver Characteristics:*** This section provides detail about characteristics of informal caregivers providing care to older adults.
- ***Care Receiver Characteristics:*** Health conditions and functional status of care receivers are highlighted in this section.
- ***Relationship Between Caregivers and Care Receivers:*** This section addresses the relationships between caregivers and care receivers, living arrangements, and more.
- ***Amount of Care Provided:*** Unique insights are offered about the amount, type, and care load of informal caregivers.
- ***Caregiving Rewards and Burdens:*** Caregiving rewards and burdens are shared from the survey findings.
- ***Service Satisfaction and Outcomes:*** Key findings about the outcomes of services, anecdotal statements by caregivers on how services affect their lives, and how services could be improved are discussed in this section.
- ***Discussion and Implications:*** The significance of informal caregivers and caregiving consequences are discussed, and an economic value formulation of informal caregiving that translates the labor contributed by informal caregiving into estimated monetary value within the paid system of care delivery is presented. Additional services that would enable caregivers to continue in their roles also are offered.

Objectives and Methodology

In 2008, NYSOFA undertook a statewide Caregiver Support Programs Participants Survey to achieve the following three primary objectives:

- Describe the caregiver population who are using NYSOFA/AAA caregiver support programs and services;
- Understand and quantify the impacts of caregiver support services; and
- Use the results to help inform and improve the programs offered through NYSOFA/AAAs.

The survey was conducted by mail from mid-May to mid-June, 2008. A sample of 1,109 caregivers was randomly selected from a stratified random sample of 30 of New York's 59 AAAs using caregiver support program participants lists to draw the sample population of caregivers who received caregiver support services in State Fiscal Year 2006 (April 1, 2006 to March 31, 2007) (see Appendix C for Methodology and Limitations). Of the 1,109 caregivers included in the sample, 607 responded to the survey, representing a response rate of 55 percent (see Appendix D for Detailed Response Rate). This response rate exceeded the conventional expectations for a mail survey, which is usually below 35 percent. The survey instrument was developed through a collaborative effort of NYSOFA staff and the Caregiver Survey Advisory

Committee.² The instrument included questions on caregiver characteristics, care receiver characteristics, relationship between caregivers and care receivers, caregiving involvement, caregiving rewards and burdens, and service satisfaction and outcomes. While this survey has applied a rigorous random sampling methodology, the findings of this survey are limited to caregivers who are either currently receiving formal services from NYSOFA/AAA’s caregiver support programs or have received services during the previous year. Therefore, characteristics explored in this survey can only be generalized to caregivers in NYSOFA/AAA caregiver support programs, which may be different from the general caregiver population (see Appendix E for Sample Weighting Scheme).

The results obtained from the caregivers who responded to the 2008 Caregiver Survey are highlighted in this Report. Throughout this Report, the term “caregiver” will be used to refer to those caregivers served by NYSOFA/AAA caregiver support programs.

Caregiver Characteristics

This survey focused on caregivers of older adults who use NYSOFA/AAA caregiver support programs, which is different from most national surveys³ of the general population of caregivers. The typical caregiver in the New York aging services system is a 64-year-old female, who has either high school or some college education, and spends more than 40 hours a week providing care to her mother. The following descriptions provide gender, age, ethnicity, marital status, education, and household income characteristics of caregivers who responded to the survey.

Gender

The majority (79 percent) of those providing care to older family members and friends are female.

Age of Caregiver

Caregivers’ ages range from 32 to 94, with an average age of 64.

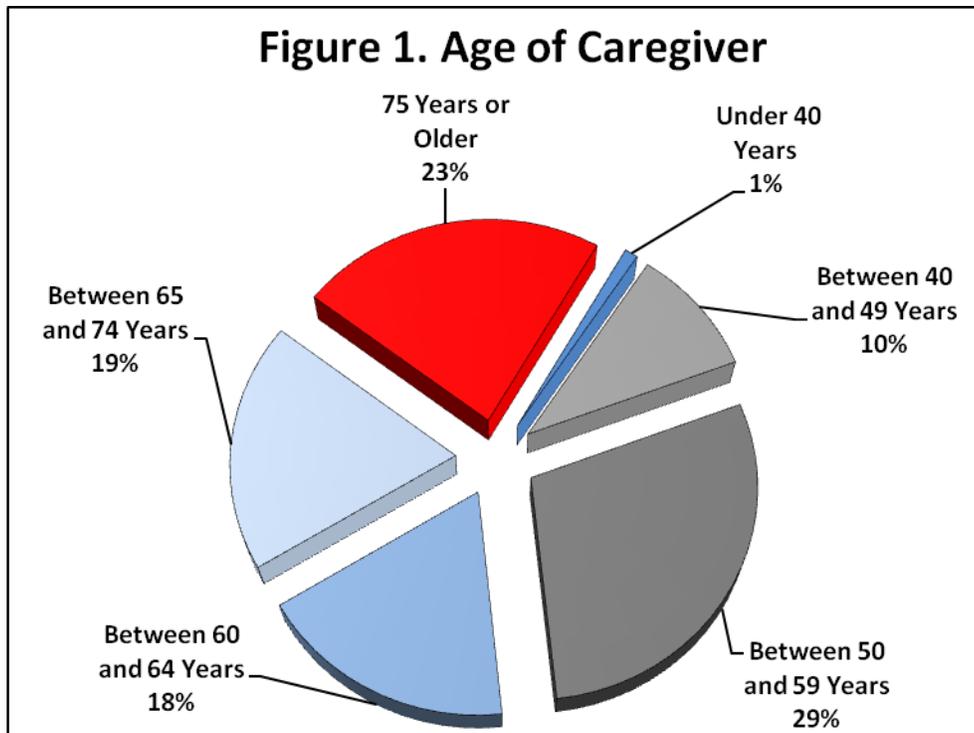
- 1 percent of the caregivers are under age 40;
- 10 percent are between ages 40 and 49; and
- 29 percent are between ages 50 and 59.

The majority (60 percent) of the caregivers are older adults themselves.

- 18 percent are between 60 and 64;
- 19 percent are between 65 and 74; and
- 23 percent are aged 75 or older.

² A Caregiver Survey Advisory Committee, consisting of NYSOFA staff, AAA Directors and Caregiver Support Program Coordinators, was established in 2005 to give advice on the development of the survey instrument and method of data collection (see the Acknowledgements section for a list of committee members).

³ Most of the national studies are based on the general population of caregivers who care for individuals of all ages and all disabilities, which are different from this survey of caregivers who care for older adults with serious health conditions and functional disabilities.



Race and Ethnicity

In terms of ethnicity, the majority (93 percent) of caregivers are non-Hispanic and 7 percent are Hispanic.

Regarding race:

- 87 percent are white/Caucasian;
- 7 percent are black/African Americans;
- 2 percent are American Indians;
- 2 percent are Asian Americans; and
- 2 percent are mixed race or ethnicity.

Marital Status

- The majority (66 percent) of caregivers are married;
- 9 percent are widowed;
- 16 percent are either divorced or separated; and
- 9 percent are single - never married.

Education

Most of the caregivers have a high school degree or beyond:

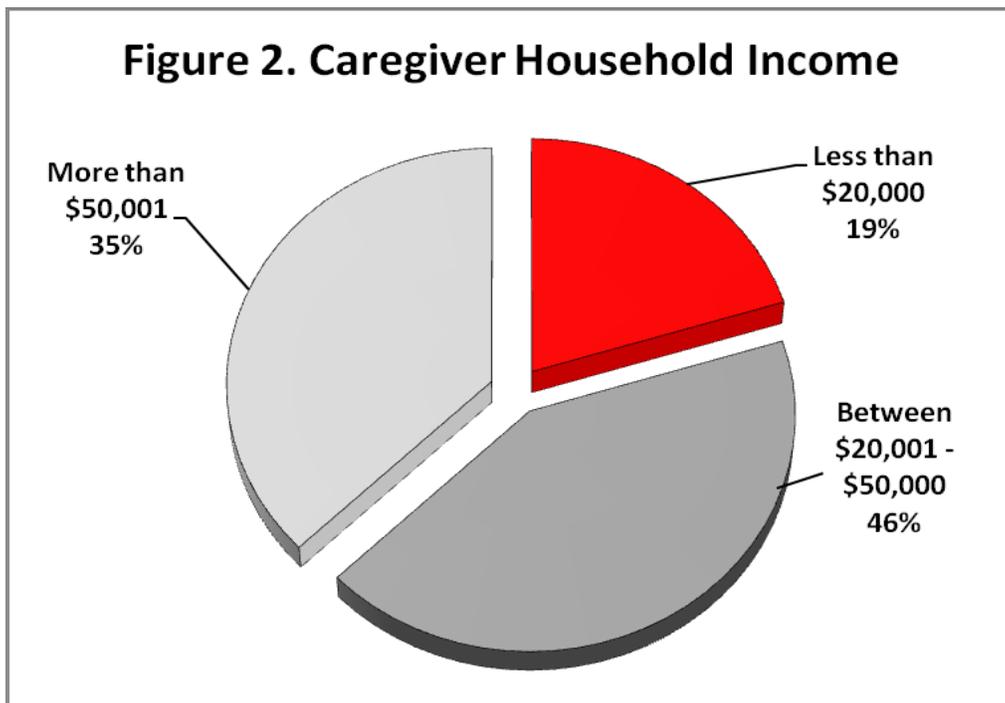
- 30 percent have less than high school or graduated high school;

- 29 percent have some college education, but without a degree;
- 15 percent are college graduates; and
- 26 percent have advanced or professional degrees.

Household Income⁴

Of those caregivers who reported their income (80 percent of survey respondents):

- 19 percent of caregivers reported that their household incomes did not exceed \$20,000;
- 46 percent reported household income between \$20,001 and \$50,000; and
- 35 percent reported household income of \$50,001 or more.



Caregivers who live alone tend to have lower incomes:

- 35 percent reported having household incomes less than \$20,000 a year;
- 45 percent have household income between \$20,001 and \$50,000; and
- 20 percent have household income of \$50,001 or more.

⁴ Household income includes caregiver's wages, social security, retirement income, public assistance, and income of everyone who lives with the caregiver.

Care Receiver Characteristics

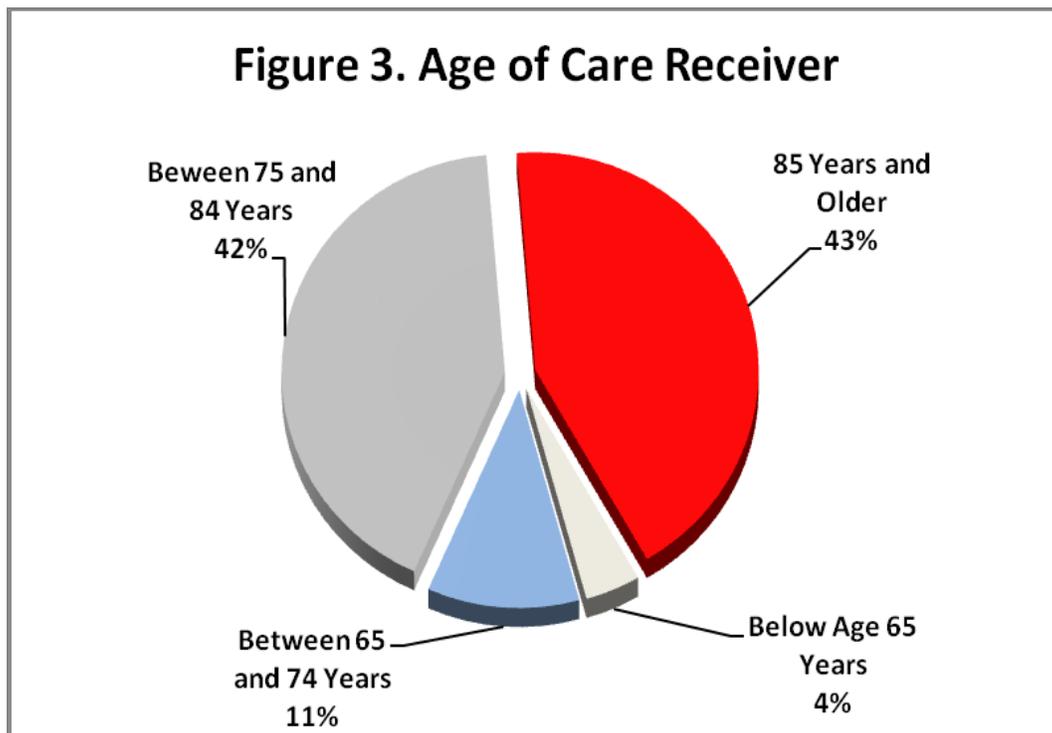
While there are a considerable number of national caregiver surveys that have provided detailed information on caregivers' characteristics, information on care receivers' characteristics are rarely included. Nonetheless, one characteristic that is well documented in the national studies is that older dependent care receivers are more likely to be women (National Alliance for Caregiving and AARP, 2004; Walker, 1995).

Gender and Age of Care Receivers

Similar to most of the national caregiver survey data, care receivers with caregivers served by New York caregiver support programs and services are more likely to be female (64 percent) than male (36 percent). A majority (85 percent) of the care receivers are aged 75 or older. The average age of care receivers is 82.3, and the oldest care receiver is aged 102.

- 4 percent of care receivers are below the age of 65;
- 11 percent are between ages 65 and 74;
- 42 percent are between ages 75 and 84; and
- 43 percent are aged 85 or older.

Those older care receivers, aged 85 or older, are a very vulnerable population. With advanced age, they are more likely to have health problems and be limited in daily activities of living. They also have a higher probability of entering into a nursing home due to their health status and condition.



Care Receivers' Health Conditions

Caregivers using New York aging services provide care to older adults with significant health needs:

- 94 percent of the caregivers reported that their care receivers had at least one health problem;
- The most prevalent health condition of care receivers in this study was Alzheimer's disease or other dementia: 75 percent of the caregivers reported that their care receivers had been told by a medical doctor that they had this condition;
- The second most prevalent health condition was high blood pressure: 73 percent of caregivers reported that their care receivers had been diagnosed with this condition; and
- Other common health conditions include eye or vision problems, arthritis, depression or anxiety, high cholesterol, hearing problems, and heart disease.

Functional Status of Care Receivers

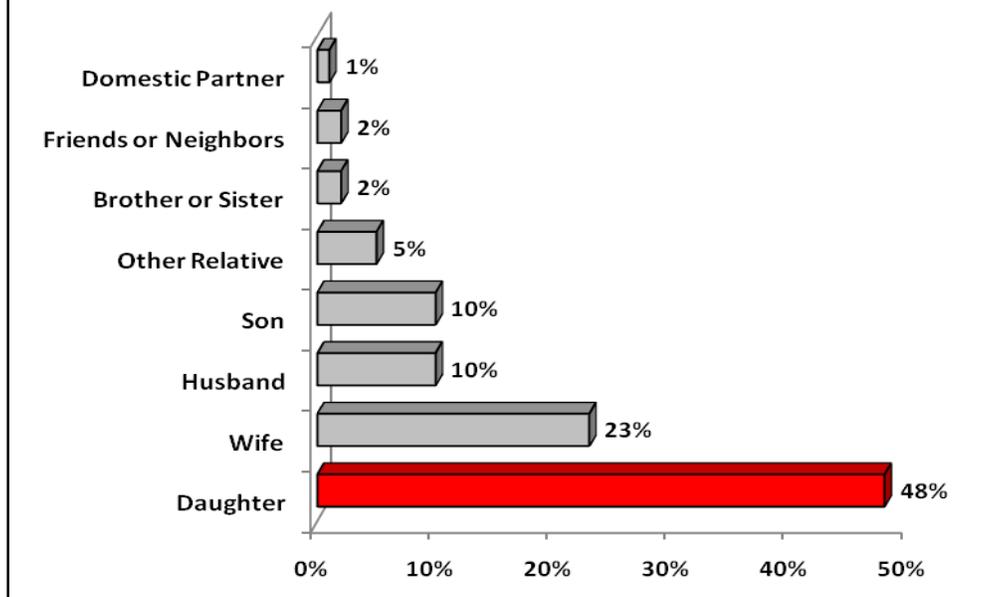
Findings from this survey show that care receivers cared for by caregivers being served by NYSOFA/AAA services and programs are frail and have many functional limitations:

- A majority (85 percent) of caregivers also reported that their care receivers have at least one functional impairment, such as walking, getting around inside the home, dressing, taking a bath or shower, and eating;
- Of those care receivers who have functional limitations, 79 percent of them have three or more activities of daily living limitations as reported by the caregivers; and
- The top three prevalent functional limitations are: taking a bath or shower (75 percent), walking (74 percent), and dressing (68 percent). Other functional limitations include: using the toilet (56 percent), getting in or out of a bed or chair (63 percent), getting around inside the home (61 percent) and eating (45 percent).

Relationship Between Caregivers and Care Receivers

The person most likely to be providing care to an older person is a daughter (48 percent), followed by a wife (23 percent), a husband (10 percent), and a son (10 percent). Other relatives, such as sisters and brothers, comprise 2 percent, and nieces, nephews, or grandchildren, comprise 5 percent of the caregivers. Older individuals also receive care from friends or neighbors (2 percent) and domestic partners (1 percent). The predominance of daughters and wives in caregiver roles are consistent with national survey data (National Alliance for Caregiving and AARP, 2004; Stone, et al., 1987).

Figure 4. Relationship between Caregivers and Care Receivers



Living Arrangements

A significant number of the caregivers surveyed live with their care receivers:

- 54 percent live together with their care receivers;
- Another 24 percent of care receivers live alone; and
- 22 percent have other living arrangements.

Caregivers who live with their care receivers tend to be primary caregivers:

- 92 percent of them reported that they provide at least half of the care to their care receivers;
- The remainder of help is usually supplemented by other caregivers and/or formal services.

Role of Caregivers

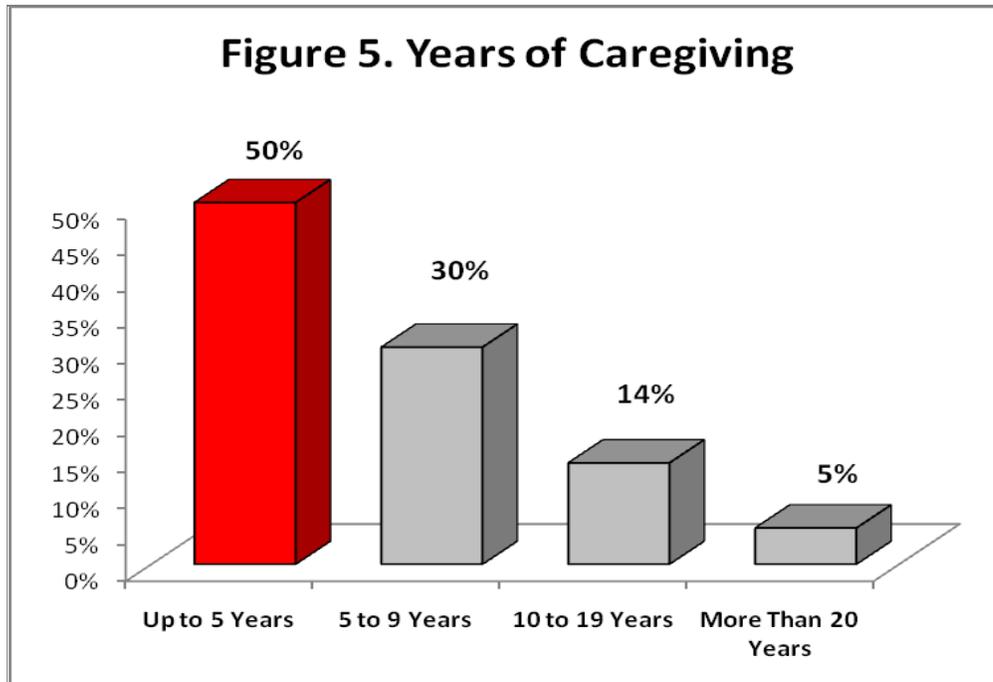
The majority of caregivers are primary caregivers:

- 75 percent provided all or nearly all care to the care receiver;
- 9 percent provided about half of the care; and
- Only 16 percent provided less than half of the care.

Years of Caregiving

The duration of caregiving ranged from less than a year to over 20 years and, on average, caregivers spent 6.2 years providing care to care receivers. The length of time caregivers provided care was as follows:

- 50 percent of the caregivers provided assistance from less than one to four years;
- 30 percent provided care for five to nine years;
- 14 percent provided care for 10 to 19 years; and
- 5 percent provided care for 20 years or longer.



Amount and Types of Care Provided to the Care Receiver

Amount of Care Provided

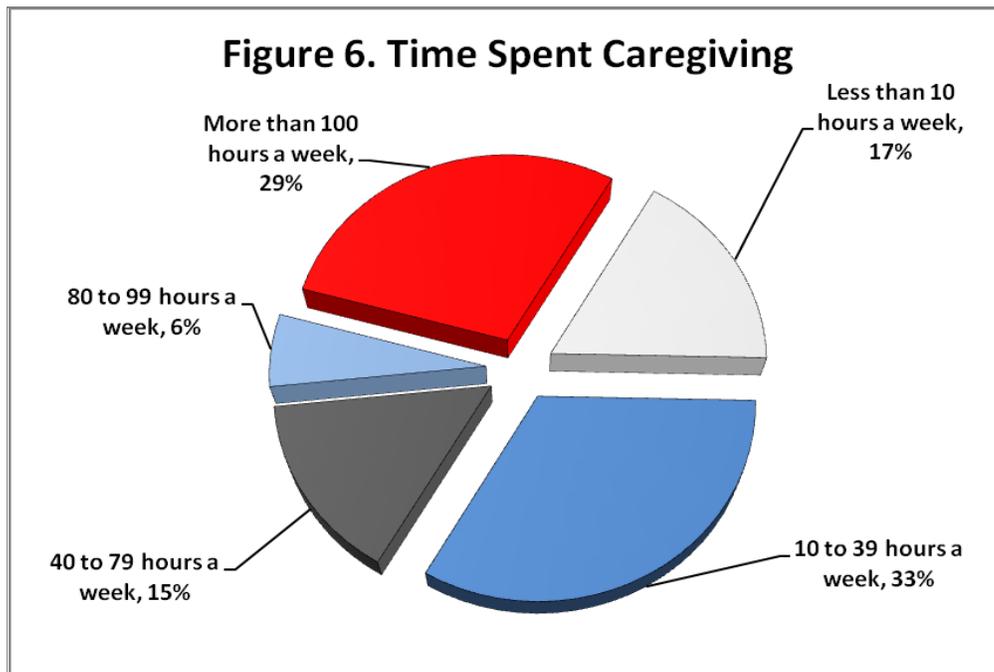
Caregivers in New York's aging services network system are providing significant amounts of care, higher than the amount of care reported by caregivers in national studies. For example, caregivers served in New York caregiver support programs report spending an average of 62.6 hours a week providing care⁵. This is considerably higher than the national average of 21 hours estimated in a recent AARP report (2008), which includes caregivers of all ages and all disabilities. This noteworthy difference in the amount of care provided by caregivers in this

⁵ The finding of New York caregiver support program participants' greater involvement with caregiving tasks than the national average is corroborated by another study of caregivers of older adults served through California Caregiver Resource Centers, which indicated caregivers in those Centers devoted an average of 85.4 hours a week of care to their care receivers (Family Caregiver Alliance, 2008).

study is likely due to differences between this survey of caregivers of older adults, contrasted to most national surveys of caregivers, which include caregivers of various ages and care receivers of all levels of disability. Caregivers in this study are exclusively caregivers of older adults, and most of the care receivers have serious health problems and significant functional limitations, leading to a need for more supportive care.

Overall, the amount of caregiving hours that caregivers provided ranged from less than 10 to as much as around-the-clock care, or care provided 24 hours a day, 7 days a week. The survey findings show that:

- 17 percent of caregivers provided less than 10 hours a week of care;
- 33 percent provided 10 to 39 hours of care;
- 15 percent provided 40 to 79 hours of care;
- 6 percent provided 80 to 99 hours of care; and
- 29 percent provided more than 100 hours of care – close to around-the-clock care to their loved ones.



Of those caregivers reporting that their care receivers have Alzheimer’s disease or other dementia, 46 percent reported that their care receivers cannot be left alone and that they provided an average of 10.3 hours of care per day. That amount of care equates to more than a full-time job.

Caregivers who live with their care receivers also reported that they provide considerably more care than caregivers who do not live with their care receivers. For instance, caregivers reported that they provided an average 90.4 hours per week of help to their care receivers, as compared to

an average of 29.9 hours of care per week by non-co-resident caregivers.⁶ The heavy involvement of caregivers who reside with the care receivers may be attributable to the increased likelihood that their care receivers are more likely to need around-the-clock care.

Types of Care Provided

While caregivers supplement their care with formal services such as home care, case management, home delivered meals, and adult day care services from NYSOFA/AAA, they continue to perform numerous activities to assist their loved ones to live at home in the community. The care and assistance that caregivers provided ranged from 24 hours a day care or supervision to assisting in specific tasks, such as:

- Transportation, including going to shopping or to the doctor's office (96 percent);
- Financial management, including keeping track of bills, checks or other financial matters (91 percent); and
- Arranging for care or services (86 percent).

Other assistance includes: housekeeping, such as preparing meals, doing laundry and cleaning the house (86 percent); arranging for home repair (82 percent); helping with medical needs, such as assisting in taking medicine or changing bandages (79 percent); performing home repair (77 percent); personal care, such as assisting in dressing, bathing, getting to the bathroom, and eating (68 percent); and paying for services (68 percent).

Care Load

Caregivers in New York caregiver support programs tend to have a heavy care load. For example:

- 36 percent of the caregivers reported that their care receivers cannot be left alone at home; and
- 42 percent reported that their care receivers can only be left alone for short periods of time, but need to be checked in person several times a day.

In addition, 73 percent of those caregivers whose care receivers cannot be left alone reported that they are responsible for 24 hours a day care or supervision.

⁶ The survey questionnaire did not ask caregivers the amount of time they spent on each specific task. Thus, the amount of time reported by caregivers may include a mix of various types of care including hands-on care, housework, and time spent on supervision.

Caregiving Rewards and Burdens

Caregiving Rewards

Although caregiving can be stressful, it also can provide positive benefits and rewards to caregivers. In fact, many survey respondents reported positive emotional rewards. Caregivers surveyed reported that at least sometimes they feel caregiving gives them a sense of:

- Helping the care receiver (99 percent);
- Satisfaction (92 percent);
- Helping family (90 percent);
- Accomplishment (90 percent);
- Being appreciated (87 percent); and
- Have companionship (67 percent).

Caregiving Burdens

There also may be some negative consequences to caregiving, including financial, emotional, and physical strain for caregivers. Caregivers indicated that they at least sometimes feel the following burdens:

- Emotional strain (90 percent);
- Not having enough time for self (86 percent);
- Causing physical stress (77 percent);
- Conflicts with social life (74 percent);
- Affecting health (74 percent);
- Not having enough time for family (72 percent);
- Interference with work (59 percent); and
- Financial burden (53 percent).

Service Satisfaction and Outcomes

Caregiver Support Services Utilization and Satisfaction

When asked about where caregivers first heard about family caregiver support programs in the aging services network, the top three sources of information were:

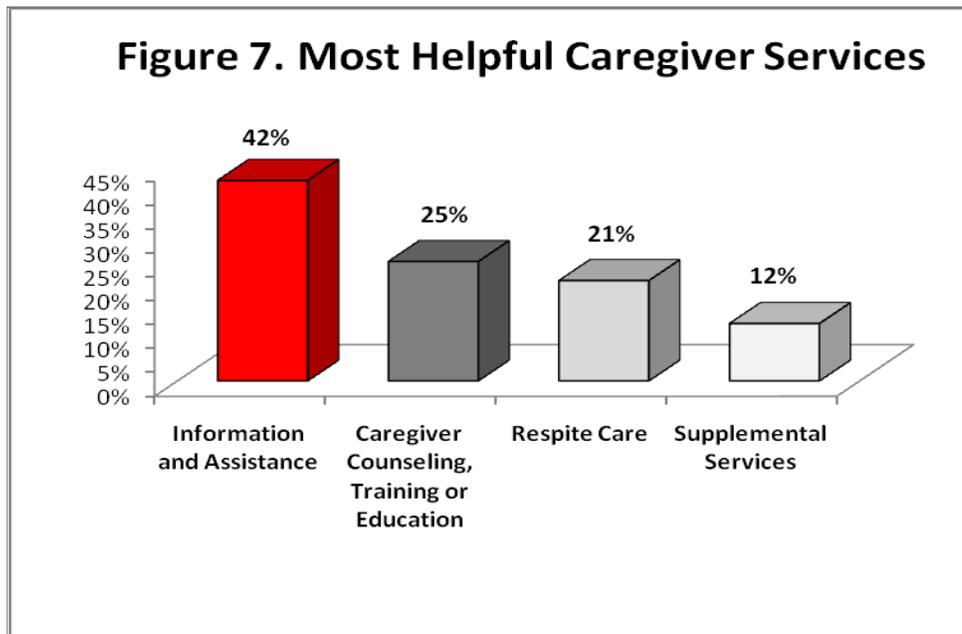
- From family or friends (22 percent);
- The state (NYSOFA) or local office for the aging (AAA) (19 percent); and
- A case manager or a social worker (14 percent).

Other sources of information include: a community organization (e.g., senior center, Alzheimer's Association, caregiver support group, Veterans Hospital, United Way Hotline, Senior Newsletters, and website), a physician or hospitals, TV/radio/newspaper, and other media.

The top three caregiver support services caregivers reported that they received are:

- Information and assistance (72 percent);
- Respite care (47 percent); and
- Caregiver counseling, training or education (43 percent).

When asked about which of the caregiver services was the most helpful, caregivers reported that information and assistance was most helpful (42 percent), followed by caregiver training or education (25 percent), respite care (21 percent), and supplemental services (12 percent). It is worth noting that information and assistance is a key function of NYSOFA/AAAs in assisting older adults and caregivers in gaining access to aging services programs. This service also helps older adults and caregivers identify and gain access to services in their communities.



When asked about how they would rate the overall quality of services they received,

- 63 percent of the survey respondents rated the services as excellent or very good;
- 24 percent rated the services as good; and
- 14 percent rated the services as fair or poor.

Eighty-six percent of the caregivers responding to this survey would recommend caregiver services to a friend.

Care Receiver Support Services Utilization and Satisfaction

The top three home and community-based services that dependent older adults received are: information about services (44 percent), home care (40 percent), and case management (31 percent).

When asked about how caregivers rate the overall quality of the care receiver services:

- 64 percent of the survey respondents rated the services as excellent or very good;
- 27 percent rated the services as good; and
- 12 percent rated the services as fair or poor.

Eighty-four percent of the caregivers would recommend the care receiver services to a friend.

Benefits of Caregiver and Care Receiver Services

Caregivers reported that the services they received assisted them in providing care for care receivers in many ways. For example:

- 73 percent stated the services resulted in benefits to care receivers;
- 59 percent suggested that the services enabled them to provide care longer; and
- 56 percent stated that the services helped them be more confident about caregiving.

Other benefits from the services include: helped caregivers better understand how to get services, improved caregivers' knowledge about care receivers' illness, helped them feel less stress, gave them more personal time, and assisted them in receiving other benefits.

Service Outcomes

The mission of NYSOFA/AAAs is to assist older adults to live as independently as possible in their home in the community for as long as possible. Survey responses demonstrated that the services provided to caregivers and care receivers help achieve this goal.

When caregivers were asked about whether care receivers would continue to live in the same home if caregiver and care receiver services had not been provided, only 48 percent of the survey respondents said that the care receivers would be able to stay in their current home if the services had not been provided, while 52 percent reported that their care receivers would not be able to continue to live in their homes if NYSOFA/AAA services had not been provided.

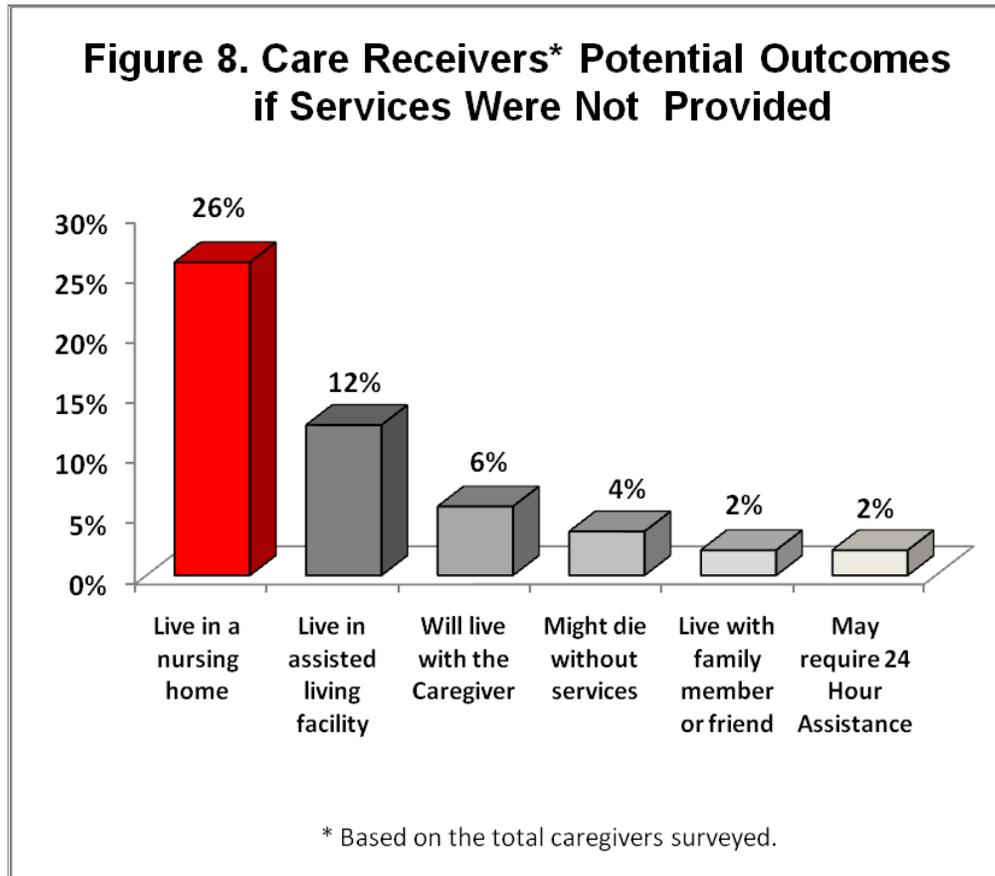
Of the 52 percent of caregivers who reported that their care receivers would not be able to continue living in their same home without aging network services, 50 percent of this subgroup reported that the care receiver would live in a nursing home if the services had not been provided; 24 percent reported that the care receiver would live in an assisted living facility; 11 percent reported that the care receiver would move in with the caregiver; 7 percent reported that the care receiver might have died without services; 4 percent reported that the care receiver would live in the home of another family member or friend; and 4 percent reported that the care receiver might be in a hospital, rehabilitation center or have around-the-clock help.

Projecting the survey findings to be applicable to care receivers of the total surveyed caregivers, the potential outcomes for care receivers if aging network services had not been provided include:

- Would live in a nursing home (26 percent);
- Would live in an assisted living facility (12 percent);

- Would move in with the caregiver (6 percent); and
- Might have passed away (4 percent).

Other possible outcomes of care receivers if aging network services had not been provided include: might live in the home of another family member or a friend (2 percent); might enter into a hospital or a rehab center, or might have around-the-clock help (2 percent).



Impacts of Services on Caregivers’ Lives

Many caregiver survey respondents provided anecdotal statements about how caregiver support programs and services affected their lives. They commented on how the services helped to reduce their burdens, relieve stress, and enable the care receivers to remain at home. A frequently used term was that the service was a “godsend.” The top five themes were:

- Less isolation and increased emotional support from others;
- Experiencing less stress, learning how to cope better and having an easier life;
- Feeling more free, having more time to work, do chores, and take care of oneself and their family;
- Having a better understanding of the caregiver role and the care receiver ’s condition; and
- Having a better understanding of how to provide care and link up to other services.

Additional statements made by caregivers about the impacts of services are included in Appendix B, “Caregivers Comments: Impacts of Services on Caregivers’ Lives.”

Additional Help and Information that Would Be Valuable

While the majority of caregivers rated the services they received as either excellent or very good and are likely to recommend those services to a friend, they also indicated that they would like to have additional help. The survey asked respondents what additional or new kinds of services or help would be valuable to them. The top two areas indicated by caregivers are: tax credits or tax breaks (71 percent) and respite care (63 percent).

- **Tax credits or tax breaks:** Caregiver research literature reported that caregivers often help pay for health care, medication, and long term care services, in addition to covering the costs of food, home maintenance, and transportation (Evercare, 2007). Close to three quarters of caregivers who responded to the survey identified tax credits or tax breaks as additional help they would like to obtain, which indicates that caregivers are in need of financial assistance to address the cost burdens they shoulder, in addition to the emotional and time costs of their caregiving responsibilities.
- **Respite care:** Another key area for which caregivers would like additional help is respite care. Respite is a service that provides temporary relief to caregivers so they have time to attend to their family’s needs, participate in a support group, attend a class to learn caregiving skills, or simply have time for themselves. Past research suggests that respite care can relieve burdens of caregiving, prevent “burnout,” and enable families to continue to care for loved ones.

Other services that caregivers identified as being valuable to them include help with: financial assistance to pay for services, housekeeping, transportation, personal care, adult day services, meal preparation, getting other family members involved, and shopping.

In terms of additional or new kinds of information that would be valuable to caregivers, the top two types of information identified in the survey are: information/help in working with formal agencies (88 percent) and information about changes in laws (87 percent).

- **Information about how to work with formal agencies:** Because caregivers' responsibilities expand far beyond carrying out daily living tasks and often include identifying, coordinating and arranging for home and community-based long term care for their loved ones, they need information on how to navigate the complex health and long term care system and need unbiased and accurate information on available long term care services and supports within their community. The **NY Connects: Choices for Long Term Care** program can address this need as it is designed to help individuals identify and access appropriate levels and types of services. However, there is a need for more public education and marketing of **NY Connects** in order for caregivers to become more aware of its availability.

- **Information about changes in laws:** Caregivers often have law-related concerns about older adults in their care, including legal issues surrounding long-term care, surrogate decision-making, individual rights, guardianship, housing, social security, elder abuse, Medicare, Medicaid, and other public benefit programs. In addition, caregivers also need to be aware of certain rights they are entitled to. For example, under the federal Family Medical Leave Act and other state provisions, they are allowed to take a leave to care for their loved ones without losing their jobs. Knowing what laws have been changed and how the changes may affect them can ease their stress and help them to care for their loved ones longer.

Other additional information assistance caregivers suggested include: having a centralized caregiver helpline, help in understanding how to pay for and select a nursing home, counseling services, how to care for people with disabilities, information about health and long term care insurance, and housing.

How Services Could Be Improved

While the majority of the caregivers responding to the survey are satisfied with the services they receive, they also see opportunities for improvement. According to caregivers, the top five areas for improvement are as follows:

- Increasing the amount of current services they receive (79 percent);
- Providing services in a less complicated manner, e.g., less bureaucracy and less paper work (78 percent);
- Providing services in a more timely manner, including starting services sooner, providing services when needed, and shorter waiting period (73 percent);
- Providing services in a more consistent manner, e.g., having the same worker each time (63 percent); and
- Easier to access services (62 percent).

Other aspects of service that caregivers think could be improved include: providing services in a more reliable manner (e.g., workers come as scheduled), having more competent workers (better skills and professional demeanor), having more personable workers (friendly and respectful), and providing more culturally diverse services (e.g., having more bilingual staff and ethnic-sensitive services). These suggestions provide valuable information to inform policy makers and program administrators on how to improve services; however, additional information is needed in order to specifically identify improvement opportunities for each of the services and develop targeted strategies to enhance service delivery.

Discussion and Implications of Survey Results

Previous research shows that the vast majority of older adults with long-term care needs receive care from informal caregivers (Thompson, 2004). The Health and Human Services Assistant Secretary for Planning and Evaluation (2003) estimated that about 7 million caregivers in the United States provide informal care to older people who need assistance with activities of daily

livings (ADLs) or other activities in order to live at home in the community. It is anticipated that the aging of society will put more demands on informal caregivers and more individuals will be called upon to be caregivers.

While the literature has long documented that caregivers provide a substantial amount of care and support to older relatives and friends, specific information about the impacts of NYSOFA/AAA caregiver programs and support services has not readily been available to policy makers and program managers. The results of this survey provide concrete, detailed information about the care provided to dependent older adults with significant needs as well as the supports provided to caregivers and care receivers through NYSOFA/AAA services and programs in New York State. Specifically, the survey findings are useful in order to:

- Understand the profile of caregivers in NYSOFA/AAA caregiver support programs and services, and understand the dynamics of their caregiving experience;
- Provide an estimate of the amount of informal caregiving provided to older adults in New York;
- Understand and provide concrete, specific evidence about the impacts of caregiver and care receiver support services; and
- Identify new areas to address that would enable caregivers to best continue in their caregiving roles.

The Significance of Informal Caregivers and Caregiving Consequences

The survey shows that caregivers using NYSOFA/AAA services and programs provide substantial care to vulnerable older adults with significant needs. For example, close to 50 percent of the dependent older adults are aged 85 or older, and a majority of them (79 percent) have at least three activities of daily living (ADL) limitations. Many of them also have health conditions such as Alzheimer's disease or other dementia, high blood pressure, vision problems, and/or arthritis.

Because these dependent elders require intensive care, caregivers bear immense burdens. The top three caregiving burdens reported by caregivers were emotional strain, lack of time for oneself, and physical stress. While informal caregivers usually undertake caregiving tasks willingly and find satisfaction from the experience, prolonged stress from caregiving is hard on caregivers emotionally. Emotional strain may be manifested in: feeling frustrated, angry, drained, guilty, helpless, or uncertain (Gray, 2003; Thompson, 2004). Such emotional strain often puts caregivers at risk of depression, anxiety, drug dependency, or other mental health problems (Haley, Levine, Brown, & Bartolucci., 1987; Miller et al., 2001; Miller & Montgomery, 1990; Young & Kahana, 1989).

In addition, caregivers reported that because of caregiving they didn't have enough time for themselves. As a result, many of them feel fatigue, a loss of self identity, and lower levels of self esteem (Mack, Thompson & Friedland, 2001; Thompson, 2004). Physical strain is another frequently reported caregiving burden. The analysis from this survey revealed that caregivers provided significant assistance to their care receivers in activities of daily living such as bathing, dressing, walking, personal hygiene, etc. Such assistance can be physically taxing, especially if their care receivers are bedridden or wheelchair-bound. The majority of caregivers are older

adults themselves (see Caregiver Characteristics section of this Report), and intense physical stress may affect their own health. As pointed out by many researchers, caregiving burden and stress are linked to serious health consequences, including increased risk of heart disease, high blood pressure, poorer immune function, and lower perceived health status (Kiecolt-Glaser et al., 1991; Schulz et al., 1997; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Vitaliano, Zhang, & Scanlon, 2003). Furthermore, a study by Schulz and Beach (1999) found that elderly caregivers who are experiencing caregiving-related stress have a higher risk of mortality than their non-caregiving peers. Because of the potential physical and emotional stress from caregiving responsibilities and the increasing numbers of informal caregivers, the stress of caregiving is now considered to be a public health concern (Fox-Grage & Gibson, 2006; Levin, 2006).

Economic Value of Informal Caregiving

The value of the labor contributed by informal caregivers is substantial, yet the actual value of such uncompensated care is difficult to estimate. However, it is well recognized that the market value of the unpaid labor of informal care is greater than the cost of paid home care assistance (Houser, & Gibson, 2007). According to a recent AARP Report (Houser, & Gibson, 2008), family caregivers who care for those who are aged 18 or older provided an estimated economic value of about \$375 billion in the United States and \$25 billion in New York State. The AARP report stated that the economic value of informal caregivers exceeds total Medicaid expenditures for nursing home and home and community-based services combined.

As stated in the previous section, caregivers in NYSOFA's survey provide intensive care and/or supervision to a very old and frail population; many of whom have significant health problems and functional limitations. Caregivers reported that they spent an average of 62.6 hours a week providing care. This amounts to an estimated total of 3,265,101 days per year of care being provided by all caregivers in NYSOFA/AAA caregiver support programs and services. The finding in this study – of caregivers' greater involvement with caregiving tasks than the national average – is corroborated by another study of caregivers of older adults served through California Caregiver Resource Centers that indicated caregivers in those Centers devoted an average of 85.4 hours a week of care to their care receivers (Family Caregiver Alliance, 2008).

Applying the methodology used in AARP's 2008 report, the estimated caregiving value is \$10.61 per hour (see Appendix F, Methodology for Estimating Economic Value of Caregiving). Thus, if the work of the 24,073 caregivers participating in NYSOFA/AAA caregiver support programs and services had to be replaced by what would be paid to home care workers, the total caregiving value would be about \$16 million a week and close to \$832 million per year in New York State.

Impacts of NYSOFA/AAA Caregiver and Care Receiver Support Services and Programs

Because of potential physical and mental health consequences, informal caregivers of dependent older adults are in need of formal services and supports to help alleviate their burden and stress. Caregiver support programs and services can assist caregivers in getting information on how to obtain home and community-based services to supplement the care provided, accessing

temporary relief from their care load, and obtaining training and education on how to care for the special needs of their loved ones. Some services also allow families to purchase goods or services (e.g., assistive devices, home modifications) that are helpful to meet their needs and those of their loved ones. These supports, in turn, enable caregivers to continue in their caregiving role in support of older care receivers. It is evident from the survey results that NYSOFA/AAA services and programs have a positive impact upon caregivers and their loved ones and helps to ease the economic burden on our health and long-term care systems.

Conclusion

Results from the Caregiver Support Programs Participants Survey provide detailed information that: describes the caregiver population who receive services from NYSOFA/AAA caregiver programs; expands our understanding about the importance of informal caregivers in caring for dependent older adults; and details the value of aging network caregiver support services in New York.

Survey results also yielded detailed information about the patterns and consequences of caregiving by informal caregivers to older adult spouses, parents, parents-in-law, other relatives, and friends. Results found that caregivers using NYSOFA/AAA caregiver support programs and services provide care to care receivers with a relatively high level of impairment and need for support. The survey results also showed that caregiver support services and community resources help caregivers to provide care longer and help to delay or prevent nursing home placement of dependent elders.

Furthermore, the information collected from the survey helps New York to recognize the strengths and effectiveness of the current service delivery system, identify areas for improvement, and develop programs and services to support caregivers to address the consequences of stressful aspects of the caregiving experience. The findings of this survey deepen our understanding about informal caregiving, thereby providing valuable information to help guide public policy-making decisions and actions in New York's efforts to address the needs of caregivers in their vital role.

As greater numbers of older adults live longer and their long term care needs increase, pressure on caregivers will be exacerbated. Caregivers likely will need formal services to supplement the care they provide and support their efforts. Caregiver support programs and home and community-based services have been demonstrated to help keep caregivers from being overburdened, sustain their ability to provide care longer, and delay or prevent their loved ones from entering into a nursing home. The quantitative results from this survey further substantiate this assertion and demonstrate the value of NYSOFA/AAA programs and services in alleviating caregiving burdens and stresses and in assisting caregivers to provide care longer. In addition, many survey respondents made anecdotal comments on how the services helped to reduce their burden, relieve stress, and enable the care receivers to remain at home.

A final note: Because of the increasing importance to be knowledgeable about New York's caregivers and of caregiving issues in order to provide appropriate information and supports, future research topics that would be important to consider include learning more about caregivers

of diverse populations including non-English speaking, racial and ethnic minority groups, disabled individuals under the age of 60, and gay and lesbian caregivers. Studies on grandparents and other kin members caring for grandchildren and relatives, and about young caregivers also should be considered in order to understand the issues and challenges faced by these special caregiver populations and develop services and programs to address their needs.

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Appendix A

Detailed Tables

The following tables provide summary responses from each question and response option categories included in the Survey.

Table 1. Age of Caregiver

Age	Caregiver %
Less than 40 years	1%
Between 40 to 49 years	10%
Between 50 to 59 years	29%
Between 60 to 64 years	18%
Between 65 to 74 years	19%
Greater than 75 years	23%

Table 2. Caregiver Race and Ethnicity

Race/Ethnicity	Caregiver %
White/Caucasian	87%
Black or African Americans	8%
American Indians/Alaskan Native	2%
Asian American	2%
Others (Mixed Race or Ethnicity)	2%

Table 3. Marital Status

Status	Caregiver %
Married	66%
Widowed	9%
Divorced or Separated	16%
Never Married	9%

Table 4. Caregiver Education Level

Education	Caregiver %
Less than high school	5%
High school	25%
Some college, no degree	29%
College graduate	15%
Advanced or professional degree	26%

Detailed Tables, continued

Table 5. Caregiver Household Income

Income	Caregiver %
\$5,000 or less	2%
\$5,001-\$10,000	4%
\$10,001- \$20,000	13%
\$20,001-\$30,000	20%
\$30,001-\$40,000	11%
\$40,001-\$50,000	15%
\$50,001-\$75,000	14%
Over \$75,000	21%

Table 6. Age of Care Receiver

Age	Care Receiver %
Less than 65 years	4%
Between 65 to 74 years	11%
Between 75 to 84 years	42%
85 years or older	43%

Table 7. Care Receiver's Health Conditions

Conditions	Care Receiver %
Alzheimer's disease or other dementia	75%
High blood pressure	73%
Eye or vision problems	72%
Arthritis	70%
Depression or anxiety	64%
High cholesterol	64%
Hearing problems	57%
Heart disease	54%
Osteoporosis	47%
Breathing or lung problems	38%
Stroke	33%
Diabetes	33%
Cancer	32%
Anemia	31%
Kidney disease	16%
None	6%

Detailed Tables, continued

Table 8. Care Receiver’s Functional Status

Needing assistance in activities of daily life	Always or Very Often* (% Reporting)	Sometimes* (% Reporting)	Rare or Never (% Reporting)
Taking a bath or shower	65%	10%	25%
Dressing	50%	18%	32%
Walking	48%	26%	26%
Using the toilet	40%	16%	44%
Getting in or out of a bed or chair	39%	24%	37%
Getting around inside the home	37%	24%	39%
Eating	28%	17%	55%

*The combined percentage of these two columns equal to the total percentage of care receivers needing assistance for the specific functional limitation.

Table 9. Caregiver’s Relationship with Care Receiver

Relationship to Care Receiver	All Caregivers %
Daughter	48%
Wife	23%
Son	10%
Husband	10%
Other Relative (niece, nephew, and grandchildren)	5%
Brother or Sister	2%
Friends or Neighbors	2%
Domestic partner	1%

Table 10. Living Arrangements

Living Status	Caregiver %
Co-reside with their care receivers	54%
Care receivers live alone	24%
Other living arrangements	22%

Table 11. Role of Caregivers

Care Provided to Care Receiver	Caregiver %
All or nearly all care provided for care receiver	75%
Provide about half the care provided for care receiver	9%
Less than half the care provided for care receiver	16%

Detailed Tables, continued

Table 12. Years Spent on Caregiving

Duration of Caregiving	Caregiver %
Less than 1 to 4 years	50%
5 to 9 years	30%
10 to 19 years	14%
Greater than 20 years	5%

Table 13. Time Spent Caregiving

Amount of Hours per Week	Caregiver %
Less than 10 hours	17%
10 to 39 hours	33%
40 to 79 hours	15%
80 to 99 hours	6%
More than 100 hours	29%

Table 14. Types of Help Provided to Care Receiver

Type of help provided to care receivers	Always or Very Often* % Reporting	Sometimes* % Reporting	Rare or Never % Reporting
Going shopping or to the doctor's office	89%	7%	4%
keeping track of bills, checks or other financial matters	85%	6%	9%
Arranging for care or services	81%	5%	13%
Arranging for home repair or home modifications	75%	7%	18%
Preparing meals, doing laundry, and cleaning the house	74%	12%	14%
Medical needs (taking medicine or changing bandages)	68%	11%	21%
Performing home repair or home modifications	66%	11%	23%
Paying for care	57%	11%	32%
Personal care (dressing, eating, bathing, or getting to the bathroom)	52%	16%	32%

* The combined percentage of these two columns equal to the total percentage of caregivers providing the specific type of care to care receivers.

Detailed Tables, continued

Table 15. Care Load

Care Load	Caregiver %
Care Receivers cannot be left alone	36%
Care Receivers can be left alone for short periods of time and/ need to be check several times a day	42%
Can be left alone	21%

Table 16. Caregiving Rewards

Caregiving Rewards	Always or Very Often* % Reporting	Sometimes* % Reporting	Rare or Never % Reporting
Helping care-receiver	88%	11%	1%
Helping family	78%	12%	10%
Sense of satisfaction	69%	23%	8%
Being appreciated	62%	25%	13%
Sense of accomplishment	56%	34%	10%
Companionship	34%	33%	33%

* The combined percentage of these two columns equal to the total percentage of caregivers reported having the specific type of caregiving rewards.

Table 17. Caregiving Burdens

Caregiving Burdens	Always or Very Often* % Reporting	Sometimes* % Reporting	Rare or Never % Reporting
Causes emotional strain	60%	30%	10%
Not enough time for self	56%	30%	14%
Cause physical stress	49%	28%	23%
Conflicts with social life	47%	27%	26%
Not enough time for family	43%	29%	28%
Affecting health	33%	41%	26%
Interferes with work	28%	31%	41%
Financial burden	26%	27%	47%

* The combined percentage of these two columns equal to the total percentage of caregivers reported having the specific type of caregiving burdens.

Detailed Tables, continued

Table 18. Sources of Information on Family Caregiver Programs

Source	Caregiver %
Family and Friends	22%
NYSOFA and/ or AAA	19%
Case manager or a social worker	14%
Physician or hospital	10%
Community organizations	10%
Media, e.g., TV, radio, newspaper, etc.	9%
Others	16%

Table 19. Caregiver Services Utilization

Services	Caregiver %
Information and Assistance	72%
Respite care	47%
Caregiver counseling, training or education	43%
Supplemental services	37%

Table 20. Most Helpful Caregiver Services

Caregiver Services	Caregiver %
Information and assistance	42%
Caregiver counseling ,training, or education	25%
Respite Care	21%
Supplemental Services	12%

Table 21. Overall Quality of Caregiver Services

Rating	Caregiver %
Very good to Excellent	63%
Good	24%
Poor to Fair	14%

Table 22. Care Receivers: Service Utilization

Services	Care Receiver %
Information and Referral	44%
Home Care	40%
Case management	31%
Home delivered meals	23%
Adult day care	19%
Transportation	21%

Detailed Tables, continued

Table 23. Overall Quality of Care Receiver Services

Rating	Caregiver %
Very good to Excellent	64%
Good	27%
Poor to Fair	12%

Table 24. Services Benefits

Services	Yes %	Sometimes %
Resulted in benefit to care receiver	73%	15%
Enable to provide care longer	59%	22%
More confident about caregiving	56%	23%
Better understanding about how to get services	52%	26%
Improved knowledge about care receiver's illness	50%	18%
Less stress	37%	34%
More personal time	29%	36%
Receive other benefits (e.g., SSI, discount phone service, VA benefit)	25%	2%

Table 25. Service Outcomes

Outcomes Without Caregiver or Care Receiver Services	Caregiver %
Care Receiver would live in a nursing home	26%
Care Receiver would live in an assisted living facility	12%
Care Receiver would move in with caregiver	6%
Care Receiver might have died without services	4%
Care Receiver would live with another family member or friend	2%
Care Receiver might be in hospital/rehab center/or have around the clock help.	2%

Detailed Tables, continued

Table 26. Additional Help that Would Be Valuable to Caregivers

Additional or New Help Needed	Caregiver %
Give tax credits or tax break	71%
Respite care	63%
Help with financial assistance to pay for services	61%
Help with housekeeping	60%
Help with transportation	56%
Help with personal care	52%
Help with adult day services	53%
Help with making meals	46%
Help with getting family involved	45%
Help with shopping	40%
Help with medicine	40%
Help with money management	32%
None	31%

Table 27. Other Information that Would Be Valuable to Caregivers

Additional or New Help Needed	Caregiver %
Help in dealing with agencies	88%
Information about changes in laws	87%
A Helpline	85%
Help in understanding how to pay for nursing homes	78%
Information about counseling services	73%
Help in understanding how to select a nursing home	71%
Information how to care for disabilities	69%
Information about health/LTC insurance	64%
Information about housing	52%
Other information	27%
None	35%

Detailed Tables, continued

Table 28. How Services Could Be Improved

Additional or New Help Needed	Caregiver %
Increase the amount of services	79%
Less complicated	78%
More timely	73%
More consistent	63%
Easier to access	62%
More reliable	53%
More competent	49%
More personable	43%
More culturally diverse	30%
Other	7%

Appendix B

Caregivers Comments: Impacts of Services on their Lives

As part of the survey, caregivers had the opportunity to add narrative comments. The tone of the anecdotal responses was very positive and many caregivers felt very grateful for the services. Also of interest were responses that revolved around the themes of being a better person (n=3), being more confident (n=4) and being able to provide more care (n=6). The following is a sample of caregivers' statements in their own words about the effects of aging services:

“Services that helped most were the linking to other services that helped with paying of medical bills, application for subsidized housing, food aid, and moral support. Felt less isolated. Made my life easier.”

“These services have allowed me some flexibility in getting care receiver's personal business done; sadly I have little time available during the day for myself.”

“It gave me one day for myself 9-3.”

“Attending Alzheimer’s caregivers support group meetings was helpful and provided better understanding of problems; Helped in the long run”

“Being less stressed; you approach the individual calmer. You can think clearer - make better decisions. Having a more positive attitude reflects upon the person you are caring about.”

“The support group has given me information and emotional support.”

“I feel I am not alone; I have become more patient and understanding, more grateful for the prayers of others.”

“If it were not for the counseling I received, I don't know what I would have done. It helped me so much to cope and understand my role and choices.”

“Have a better understanding of illness and methods to deal with same. Also, alternative procedures to cope with situation.”

“TRIPS helps me with some of the transportation to a doctor, e.g., - to the podiatrist - as a caregiver I do not have to accompany my husband to the podiatrist.”

“Respite 7 days/year - this is great, but not enough time.”

“To be a better person - I enjoy it, no burned out feeling, need to give more of myself. I just love being a caregiver. I would do it again.”

Caregivers Comments: Impacts of Services on Caregivers' Lives, continued

“I struggled with a full time job, caregiving, life in general and appreciated the information from the Office of Aging, the kindness and caring from the staff. The words to help me get through many days lifted me to keep me going.”

“The services have caused me (the caregiver) to look more toward the future.”

“Enabled me to care for my sister at home for another year or so”

“Gave me information that was needed.”

“As a caregiver for both parents, one with cancer and one with dementia, it was a long learning process. When it came to services, we had hospice and aides to help with both parents. Services help give some relief, because at times you feel very helpless.”

“Helps me be more objective while still maintaining good relationship with the care receiver. I learned very good communication techniques through the caregiver resources/training program.”

“My mother in law would not be alive today were it not for the help from the Office of the Aging. We were unaware of what was available and it has successfully enriched her life.”

“It lets me breathe a little easier because a health aide is there a couple of times a week to help her - I only wish it was every day.”

“More understanding how to navigate a system that is large and confusing, full of bureaucracy, incompetence and definitely some sleazy and uncaring people.”

“Made it much easier to cope and deal with.”

“It has enabled me to continue working.”

Appendix C

Methodology and Limitations

Survey Population

The survey population focuses on individuals who participated in the New York State Caregiver Support Programs funded by Federal and State funds, including the Older Americans Act Title III E funds and state funded caregiver resources centers. According to the New York State Office for the Aging's (NYSOFA) Consolidated Area Agency Reporting System data, a total of 34,390 caregivers received caregiver support program services in State Fiscal Year 2006 (April 1, 2006 to March 31, 2007).

Survey Sampling Process

A multi-stage stratified random probability sampling methodology was developed to draw a representative sample from the statewide caseload of caregiver support program participants. The first stage involves grouping Area Agencies on Aging (AAAs) into three strata: urban, rural and suburban strata. Then a sample of 50 percent of AAAs was randomly selected in the second stage to represent the 59 AAAs in the State. In stage three, a sample of caregivers within each sampled AAA was randomly selected to represent the total caregiver support program caregiver caseload at the respective AAA.

Area Agency Sample

Before selecting the AAA samples, the 59 AAAs were first grouped into urban, suburban, and rural strata based on the NYSOFA's classification using the U. S. Census' population density data⁷ for Planning and Service Areas (typically counties or county groups). The purpose of stratifying AAAs into urban, suburban, and rural strata is to ensure area differences in availability and accessibility of family caregiver support programs and formal services were properly considered in drawing the caregiver samples. The 59 AAAs are stratified as follows:

- Stratum 1: 7 Urban AAAs (Albany, Erie, Monroe, New York City, Onondaga, Schenectady and Westchester)
- Stratum 2: 13 Suburban AAAs (Broome, Chemung, Dutchess, Montgomery, Nassau, Niagara, Oneida, Orange, Putnam, Rockland, Saratoga, Suffolk, Wayne)
- Stratum 3: 39 Rural AAAs (Allegany, Cattaraugus, Cayuga, Chautauqua, Chenango, Clinton, Columbus, Cortland, Delaware, Essex, Franklin, Fulton, Genesee, Greene, Herkimer, Jefferson, Lewis, Livingston, Madison, Ontario,

⁷ The U.S. Bureau defines urban areas as territory, population, and housing units as densely-settled areas with a Census population of at least 50,000 or urban clusters (densely-settled areas with a Census population of 2,500 to 49,999). Rural areas are defined as territory, population, and housing units outside of urbanized areas with fewer than 2,500 people or areas where people live in open country.

Orleans, Oswego, Otsego, Rensselaer, Schoharie, Schuyler, Seneca, Seneca Nation, St. Lawrence, St. Regis, Steuben, Sullivan, Tioga, Tompkins, Ulster, Warren/Hamilton, Washington, Wyoming, Yates)

Half of the AAAs were then randomly selected from each of the three strata. This resulted in a sample frame as follows:

- Stratum 1: 4 of 7 Urban AAAs were selected
- Stratum 2: 6 of 13 Suburban AAAs were selected
- Stratum 3: 20 of 39 Rural AAAs were selected

These 30 selected area agencies on aging were then contacted by phone to verify with caregiver support program coordinators that the number of caregivers served met study requirements.

Caregiver Sample Size

As mentioned earlier, NYSOFA Consolidated Area Agency Reporting System data showed that 34,390 caregivers received caregiver support services in 2007. Based on 35 percent response rate from the Office's previous mail survey experiences, the State Office calculated that a sample of 1,106 caregivers would give the Office the desired confidence interval of 95 percent and confidence level of 5 percent. In order to have equal representation from urban, suburban and rural strata, NYSOFA drew 400 caregiver samples from each stratum to yield 1,200, which exceeds the minimum of 1,106 caregivers for the total sample. The sample AAAs within each stratum then selected the number of caregivers in accordance with the proportion of their caseloads to the total caseload in the respective stratum. Each caregiver support program coordinator of the 30 selected area agencies was asked to select the sample based on the instructions given by NYSOFA. Of the 1,200 sample, 91 individuals' names were taken off from the sample list because they either moved to a different address, or not involved in caregiving directly. This resulted in a final sample of 1,109 individuals.

Caregiver Sample Selection Criteria

The Caregiver Support Program coordinators were instructed to select survey caregivers meeting the following criteria:

- Must be at least 18 years of age;
- Must be a family member, friend, or neighbor who helps care for an older individual (aged 60 or more) who lives at home; and
- Must be receiving caregiver support program services that include information, assistance, respite care, education, training or support group, and supplemental services (e.g., home delivered meals, transportation, personal emergency system) during the State Fiscal Year 2007.

The program coordinator was given a random number and instructed to go to every fifth caregiver on the list until the specified number of caregiver cases was reached.

Informed Consent and Sample Verification

Letters of informed consent were mailed out by AAA Directors to selected sample caregivers in advance so that they were informed about the upcoming survey and informal consent was obtained. The informed consent letter also provided caregivers an opportunity to confirm the legitimacy of the survey and to opt out of participating in the survey. In cases that caregivers had moved to a different address, the informed consent letter was returned to the AAAs. The AAAs then took off those caregivers who had moved or opted not to participate in the survey from the sample list and followed the instructions provided by the State Office to select substitutes for the sample. Through this sample verification and cleaning process, the final sample size resulted in 1,109. The AAAs then provided NYSOFA with caregiver's names and addresses for the mail survey.

The Caregiver Survey was administered by the Finger Lakes Geriatric Education Center (FLGEC) in May, 2008 and followed by a thank you/reminder postcard in mid-May. A second mailing of the survey was mailed during mid-June, 2008. It received tremendous statewide support from AAAs and caregiver support program participants. One hundred percent of sampled New York AAAs participated in the survey, and the response rate from caregiver support program participants was 55 percent. Both the support of AAAs and responses of program participants exceeded the expectations for a mail survey.

Limitations

The present study has several limitations that should be addressed in future research efforts. Of particular importance is that the findings of this survey are limited to caregivers who are either currently receiving formal services from the NYSOFA/AAA's caregiver support programs and services or have received services during the last year. The characteristics explored in this study can only be generalized to caregivers in the NYSOFA/AAA caregiver support programs and services, which may be different from the general caregiver population. Past literature indicates that most caregivers are reluctant to seek the support of a formal services system for fear of losing independence and control, and a majority of them also are unaware of the availability of services. As suggested by Montgomery and Kosloski (2000), caregivers often waited until crisis arose or they were overwhelmed by the demand of caregiving, before seeking help from a formal services system. Therefore, caregivers in the formal system tend to care for those loved ones who have significant needs. The results of this survey provide evidence that supports this assertion.

The survey design also suffers a few limitations in spite of the fact that considerable efforts were made in the design of the instrument and the administration of the survey. One key limitation is the method of data collection. A mail survey approach was adopted in order to give caregivers the flexibility and convenience of when to respond to the survey. However, this approach may lead to low response rates from individuals with lower literacy levels. In addition, this questionnaire was in English, and thus may have excluded non-English speaking caregivers, including immigrant populations. Furthermore, this survey focused on caregivers of older adults, without considering caregivers of young, disabled individuals and other caregiver populations,

such as gay and lesbian caregivers. Future research should consider studying caregivers of young disabled individuals, and gay and lesbian individuals. Additionally, the questionnaire should be translated into languages of the caregivers so that more caregivers can participate in the survey to provide a more comprehensive picture of caregiving issues and assessment of caregiver support services in New York.

In addition, the survey findings rely upon honest responses and good recall of the survey respondents. Thus, faulty recall on how many hours of care, on average, caregivers usually provide to their care receiver in a week would affect the results. Furthermore, this survey suffers from a lack of questions in certain areas. For example, questions such as why caregivers seek help from the formal system and the employment status of caregivers were not asked in this study. These questions may be helpful to understand how to outreach to those who are not in the current services system and the impact of caregiving on employment. Future studies should consider including questions in these areas in order to obtain a more comprehensive picture of caregiver situations, better understanding of what motivates caregivers to seek help, and techniques to improve accessibility and delivery of caregiver support services.

Appendix D

Survey Response Rate

Survey response rate by sample strata

# of Sampled Counties	Total Response	Response Rate Percent
20 Rural Counties	158	60%
6 Suburban Counties	171	74%
4 Urban Counties	278	45%
Total	607	55%

Response rate by county

County Name	Response Rate Percent	County Name	Response Rate Percent
Allegany	79%	Orleans	42%
Broome	67%	Putnam	100%
Cayuga	75%	Rensselaer	93%
Chautauqua	84%	Rockland	100%
Chemung	56%	St. Lawrence	38%
Clinton	62%	Steuben	48%
Cortland	53%	Suffolk	75%
Erie	52%	Sullivan	61%
Fulton	100%	Tompkins	48%
Genesee	35%	Warren/ Hamilton	100%
Jefferson	100%	Washington	100%
Madison	88%	Westchester	33%
Oneida	80%	Wyoming	77%
Onondaga	46%	Yates	62%
Orange	75%	NYC	45%
Total			55%

Appendix E

Sample Weighting Scheme⁸

The survey employed a multiple-stage sample design. In stage one, Area Agencies on Aging (AAAs) were grouped into three strata: urban, rural and suburban strata. Then a sample of 50% of AAAs was selected in the second stage. In stage three, a sample of caregivers within each sampled AAA were randomly selected.

Weighting of each caregiver was computed by taking the inverse of the selection probability for each sampled caregivers and adjusted for non-response. It was done in two steps: calculation of base weights and non-response adjustment.

Base Weights

The base weight is the inverse of the overall selection probability of a caregiver. The base weight of a caregiver can be obtained by calculating the base weight of an AAA and multiplying that weight by the within-AAA-level base weight of a caregiver in the caregiver support program within that AAA.

The base weight of an AAA i can be expressed as

$$a_i = \frac{1}{P_i} = \frac{M_i}{m_i}$$

and the base weight of a caregiver in a caregiver support program within an AAA can be expressed as $v_{ij} = \frac{1}{P_{ij}} = \frac{N_{ij}}{n_{ij}}$

The basic weight can be expressed as

$$w_{ij} = a_i \times v_{ij}$$

Non-response Adjustment

If n_{ij}^r denotes the number of caregivers that responded to the survey, then the non-response adjustment was calculated as follows:

$$v_{ij}^r = \frac{N_{ij}}{n_{ij}^r}$$

Final Weight

The overall adjusted weight of a caregiver within AAA i can be expressed as:

$$W_{ij} = w_{ij} \times v_{ij}^r$$

⁸ This scheme is developed based on the technical documentation of the third Administration on Aging's National Survey.

Appendix F

Methodology of Estimating Economic Value

The following three approaches were used for estimating the value of caregiving provided by caregivers in the NYSOFA/AAA caregiver support programs and services.

Approach I applies the 1999 Kaiser Family Foundation study's methodology (Arno, 1999) to estimate the economic values per hour of caregiving. The hourly value of caregiving is estimated as the average of the state minimum wage of 2008 (\$7.15), plus the 2008 Medicaid pay rate of personal care I (\$19.36) and II (\$19.67) that amounts to \$15.39 per hour. Therefore, if the work of these caregivers had to be replaced by what would be paid to the home care staff, the total caregiving costs to New York State would be \$23 million per week or \$1.2 billion per year.

Approach II applies the 2008 AARP report's methodology (Houser, Gibson, 2008) to estimate the economic values per hour of caregiving. The hourly value of caregiving is estimated as the weighted average of the state minimum wage, state home health aide median wage and the average private hourly rate for hiring a home health aide. The estimated hourly rate, according to AARP's report is \$10.61. Therefore, if the work of these caregivers had to be replaced by what would be paid to the home care staff, the total caregiving value would be about \$16 million a week and close to \$832 million per year.

Approach III applies a special methodology developed by the New York State Office for the Aging, in which it assumes that for those caregivers who reported that they provided 168 hours a week of care to their care receivers a mix of different types of care (e.g., ADL assistance, IADL assistance, and non-hands-on supervision) were provided. Therefore, the following steps were taken:

1. Separate those who stated that they provide 168 hours per week (24 hours a day, 7 days a week) assistance from those who do not provide around the clock help.
2. For those who provide 168 hours per week (24 hours a day, 7 days a week) assistance, the 2008 Medicaid live-in assistance payment rate was used to calculate the economic value of the around the clock care.
3. For those who do not provide around the clock assistance, an average number of hours of assistance was calculated and used to estimate the total hours of assistance provided by this group of caregivers per year. The total hours of care were then multiplied by the estimated number of caregivers who do not provide around-the-clock care.
4. The total value of caregiving is estimated by adding the value resulted from step 2 and step 3. This resulted in an estimated caregiving value of \$11.4 million a week and more than \$590 million a year.

Range of Estimates from the for the Economic Value of Caregiving of Informal Caregivers in NYSOFA/AAA caregiver support programs and services	
	Number of Caregivers (24,073)
Approach I (\$15.39/hr)¹	\$1,206,259,000
Approach II (\$10.61/hr)²	\$831,425,378
Approach III (mixed rate)³	\$590,196,219

1. Calculated based on the 1999 Kaiser Family Foundation study's methodology (see approach I).
2. Based on AARP's estimate of hourly value for New York (see approach II)
3. Based on 2008 Medicaid day rate of \$221.1 for caregivers providing around the clock care, plus the hourly rate of \$15.39 (approach I) for the remainder of the caregivers (see approach III).

Appendix G

New York State Office for the Aging Caregiver Support Programs Participants Survey Instrument

To obtain a copy of the instrument, please visit the New York State Office for the Aging website:

<http://www.aging.ny.gov/ReportsAndData/NYSOFACaregiverSurveyInstrument.pdf>



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