

Executive Summary

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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Executive Summary

The Caregiver Support Programs Participants Survey was funded by the federal Administration on Aging (AoA), as part of the Performance Outcomes Measures Project (POMP) under AoA Grant# 90AM3103 to test a statewide survey methodology and to assess the outcomes of caregiver support programs administered through the aging services system in New York State.

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 with daily tasks. The types of caregiver support services provided through NYSOFA and local Area Agencies on Aging (AAA) include: information and assistance, individual counseling, support groups, training, respite, and supplemental services to complement the care provided by the caregiver.

Little information has been collected to date to provide a profile of caregivers served by NYSOFA/AAA caregiver support programs and to quantify the impact of programs and services on caregivers and care recipients. In 2008, NYSOFA undertook a statewide survey to: (1) gather detailed information that describes the caregiver population who receive services from NYSOFA/AAA caregiver programs and services, (2) demonstrate the impacts of NYSOFA/AAA support programs and services on caregivers, and (3) help inform program administrators, service providers, and policy makers so that they may improve programs and services. Detailed information was collected about the demographic characteristics, functional status, health conditions, caregiving experience, and the impact of NYSOFA/AAA caregiver support programs that caregivers utilized. The *Sustaining Informal Caregivers: New York State Caregiver Support Programs Participants Survey Report of Findings on the Aging Services Network* details the survey findings, which underscore the importance of caregivers and the impact and value of NYSOFA/AAA caregiver support programs and services.

Survey: Objectives and Methodology

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 participant lists to draw the sample population of caregivers who received caregiver support services. Of the 1,109 caregivers included in the sample, 607 responded to the survey, representing a response rate of 55 percent.

Selected Survey Results

Caregiver Characteristics

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 majority (66 percent) of caregivers are married and close to one fifth of them reported that their household income is below \$20,000.

Care Receiver Characteristics

In New York's aging services network caregiver support programs, individuals receiving care from caregivers are more likely to be female (64 percent) and a majority (85 percent) of them are aged 75 or older. Many of them have significant health needs, with 94 percent of the caregivers reporting that their care receivers had at least one health problem. The most prevalent health condition of care receivers was Alzheimer's disease or other dementia; 75 percent reported this condition. Care receivers also have many functional limitations. A majority (85 percent) of them have one or more impairments in taking a bath or shower, walking, dressing, getting in or out of a bed or chair, getting around inside the home, using the toilet, and eating. More than three-quarters (79 percent) of care receivers have three or more activities of daily living limitations as reported by the caregivers.

Relationship between Caregivers and Care Receivers

The person most likely to be providing care to a dependent older adult is a daughter (48 percent), followed by a wife (23 percent), a husband (10 percent), a son (10 percent), other relatives (5 percent), a brother or a sister (2 percent), friends or neighbors (2 percent), and domestic partners (1 percent). A significant number (54 percent) of the caregivers live with their care receivers. The majority of caregivers are primary caregivers; 75 percent provided all or nearly all care to the care receiver. The duration of caregiving ranged from less than a year to over 20 years, with an average of 6.2 years.

Amount and Types of Care Provided to the Care Receiver

Caregivers participating in New York caregiver support programs are providing significant amounts of care – higher than the amounts reported by caregivers in national studies. The difference between this study and what is reported in national studies is likely because caregivers in this survey are exclusively caregivers of older adults, and most of those older adults have serious health problems and significant functional limitations, while most national surveys include caregivers providing care across the age spectrum and all levels of disability.

Caregivers served in New York caregiver support programs report spending an average of 62.6 hours a week providing care, which is considerably higher than the national average of 21 hours estimated in a 2008 AARP report. The care and assistance that caregivers provided ranged from around the clock care or supervision, to assisting in specific tasks, such as: transportation (96 percent), financial management (91 percent), arranging for care or services (86 percent), housekeeping (86 percent), arranging for home repair (82 percent), helping with medical needs (79 percent), performing home repair (77 percent), personal care (68 percent), and paying for services (68 percent). Caregivers participating in New York caregiver support programs tend to have a heavy care load: 36 percent 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 or need to be checked on in person several times a day.

Caregiving Rewards and Burdens

Caregiving can be stressful, but it also has positive benefits and rewards. Many survey respondents reported positive emotional rewards. For example, caregivers reported that at least sometimes they feel they are helping the care receiver (99 percent), have a sense of satisfaction (92 percent), are helping a family member (90 percent), have a sense of accomplishment (90 percent), feel appreciated (87 percent), and have a sense of companionship (67 percent).

Caregivers also reported some negative consequences to caregiving, including financial, emotional, and physical strain for caregivers. The burdens indicated by caregivers include: causing emotional strain (90 percent), not having enough time for self (86 percent), causing physical stress (77 percent), having 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).

Services Utilization and Satisfaction

The top three sources of information about caregiver support programs in the aging services network are: family or friends (22 percent), the state or local office for the aging (19 percent), and a case manager or a social worker (14 percent). The top three caregiver support services that caregivers received are: information and assistance (72 percent), respite care (47 percent), and caregiver counseling, training, or education (43 percent). Caregiver support services were rated as excellent, very good, or good by 87 percent of survey respondents.

The top three home and community-based services that care receivers received are: information about services (44 percent), home care (40 percent), and case management (31 percent). Care receiver support services were rated as excellent, very good, or good by 91 percent of survey respondents.

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. Seventy-three 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. Fifty-two percent reported that their care receivers would not be able to continue to live in the same home if NYSOFA/AAA services had not been provided. These caregivers suggested that potential outcomes for care receivers without the needed services might include: living in a nursing home, living in an assisted living facility, moving in with the caregiver, moving in with another member of the family or a friend, entering into a hospital or a rehab center, or having around-the-clock help.

Additional Help and Information That Would Be Valuable to Caregivers

While the majority of caregivers gave high ratings on the quality of services they received and are likely to recommend the services to a friend, they also indicated that they would like to have

additional help. The top three areas identified by survey respondents that would help support them in their caregiving role are: tax credits or tax breaks (71 percent), respite care (63 percent), and help with financial assistance to pay for services (61 percent). In terms of additional or new kinds of information that would be valuable to caregivers, the top three types of information identified by caregivers responding to the survey are: help in working with formal agencies (88 percent), information about changes in laws (87 percent), and a centralized caregiver helpline (85 percent). When asked how services could be improved, the top three areas identified by survey respondents are: increasing the amount of current services they received (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).

Discussion and Implications

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. Caregivers served by NYSOFA/AAA services and programs are a particularly vulnerable group. Over two-thirds of the caregivers said they have been providing care for three years or longer and almost one-quarter of them are aged 75 or older. Caregivers bear immense burdens resulting from the intensive care needed by many care receivers. The top three caregiving burdens reported by caregivers were emotional strain, lack of time for oneself, and physical stress. According to previous caregiving research literature, such caregiving burdens and stresses are linked to serious health consequences, including increased risk of drug dependency, mental health problems, heart disease, high blood pressure, poorer immune function, lower perceived health status, and higher mortality rate. 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.

Economic Value of Informal Caregiving

The value of the labor contributed by the caregivers served by NYSOFA/AAA services and programs is substantial even though the actual value of such uncompensated care is difficult to estimate. Applying the methodology used in AARP's 2008 Report, the total economic value of informal care provided by all caregivers served by NYSOFA/AAA caregiver support programs would be about \$16 million a week and close to \$832 million per year if the work of these caregivers had to be replaced by paid home care workers.

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 alleviate their burden and stress. Previous literature shows that caregiver support programs and services can enable 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. These documented research findings show that caregiver and care receiver support services enable caregivers to continue providing care for their loved ones and help care receivers to stay at home, preventing them from entering into nursing homes or assisted living facilities. It is demonstrated by the findings of this survey that investment in NYSOFA/AAA services and programs not only help caregivers and their loved ones, but also eases the burden on our health and long term care systems.

Conclusion

For the first time, results from the NYSOFA Statewide Caregiver Support Programs Participants Survey provide detailed information that describes the caregiver population who receive services from NYSOFA/AAA caregiver programs. The reported findings expand understanding about the importance of informal caregivers in caring for dependent older adults and the value of caregiver support services in New York. The survey results show that caregiver support services and community resources help caregivers to provide care longer, and may also help delay or prevent nursing home placement of dependent elders. Survey responses provide a robust estimate of the unpaid value of the labor contributed by the caregivers served by NYSOFA/AAA services and programs. The total economic value of informal care provided by caregivers served by NYSOFA/AAA caregiver support programs is estimated to be close to \$832 million per year if the work of these caregivers had to be replaced by paid home care workers. The survey results also inform New York State and local decision makers about the strengths and effectiveness of the current service delivery system in order to identify areas for improvement, and ways to support caregivers address the consequences of stressful aspects of the caregiving experience.

The survey is successful in providing a rich array of information about NYSOFA/AAA programs and services that support caregivers. Future research topics to be considered 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 also should be considered.

Additional Information

To read or download the complete report visit NYSOFA's web site at <http://www.aging.ny.gov/Caregiving/Reports/index.cfm>

Related reports

New York State Family Caregiver Council. (2009). *Supporting and Strengthening Caregivers in New York State: New York State Family Caregiver Council Report*. New York State Office for the Aging: Albany, NY.

Caprio, T., Katz, P, Karuza, J, and Rehse, D. (2009). *New York State Caregiver Services Survey: NY Connects Local Long Term Care Councils' Assessment of Community Caregiver Support Services*. Report to the New York State Family Caregiver Council. Finger Lakes Geriatric Education Center of Upstate New York: University of Rochester Medical Center, Rochester, NY

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