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# Caregivers reports: Key Findings



## Background:

- There are over 2.2 million informal caregivers (friends, family, neighbors) in New York State (at any point in the year, 3.1 million New Yorkers are caregivers) who provide direct care to persons of all ages with disabilities. This care is valued at \$25 billion if paid for at the market rate. It is also estimated that caregivers save the state Medicaid program over \$12 billion per year.
- Over 80% of all long-term care is provided by family members, friends and neighbors, saving New York State billions in health care and long-term care costs each year. Consequently, caregivers will continue to be an integral part of health and long-term care in New York State; without them, direct costs would incur to the state's Medicaid program.
- A study by the MetLife Mature Market Institute found that caregiving has a huge impact on private and public sector businesses, estimated to cost businesses over \$33.6 billion nationally due to worker absenteeism, turnover, workday interruptions, unpaid leave, etc.

Reports Released by the New York State Office for the Aging:  
Three reports are being released by the NYSOFA today-

- 1) Supporting and Strengthening Caregivers in New York State: New York State Family Caregiver Council Report- Provides background on caregiving, identifies issues and makes recommendations.
- 2) Sustaining Informal Caregivers: New York State Caregiver Support Programs Participants Survey: Report of Findings on the Aging Services Network - First ever profile of NY's caregivers, care receivers, economic value of caregiving, hours of care provided, and type of care provided through NYSOFA administered caregiver programs.
- 3) New York State Caregiver Services Survey: NY Connects Local Long Term Care Councils' Assessment of Caregiver Support Services - This is a gap analysis of caregiver programs in communities around the State – what is available, what is not, level of knowledge about them and recommendations/needs.

## Summary of Reports:

### *Supporting and Strengthening Caregivers in NYS:*

The Council membership includes more than 50% caregivers, and includes cross age and disability (not older adult specific) members as well as sister state agencies participating as ex-officio members. Below are key recommendations included in the report:

- Enhance Services and Programs that Support Caregivers and Care Recipients
- Increase Information and Outreach to Informal Caregivers Across the Lifespan

- Encourage Civic Engagement/Community Empowerment to Support Informal Caregivers
- Continue the Development of State and Local Infrastructure for Caregiver Services and Supports
- Expand Training and Education for Informal and Professional Caregiving
- Educate and Involve Business and Workforce in Caregiving Issues
- Improve the Rights of Caregivers
- Enhance Housing Options and Supports

*Sustaining Informal Caregivers: New York State Caregiver Support Programs Participants Survey: Report of Findings on the Aging Services Network:*

**Key Findings:**

- The typical caregiver in the New York aging network services system is a 64-year-old female, who has either high school or some college education, and spends more than 20 hours a week providing care to her mother.
- Caregivers in New York aging network system provide care to a much older and frail population, many of them with significant health problems. A majority (85%) of caregivers reported that their care receivers have functional impairments, 79% having 3 or more activities of daily living impairments and 44% of the care receivers are aged 85 or older. These care receivers require intensive care or supervision.
- Applying the methodology used by AARP's study (2007), the estimated caregiving value is \$15.39 per hour. Thus, 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 more than \$27 million a week and close to \$1.4 billion per year.
- The average age of care recipients is 82.5. With advanced age, the care recipients 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.
- 74% of the caregivers reported that a medical doctor has told them that their care receivers have Alzheimer's or dementia.
- High blood pressure has been reported by 75% of caregivers as a health problem that their care receivers have been diagnosed with.
- Other common health conditions of care receivers reported include: eye or vision problems, arthritis, depression or anxiety, high cholesterol, hearing problems and heart disease.
- The majority of caregivers surveyed are primary caregivers: 77% provided all or nearly all care to the care-receiver.
- Caregivers spend an average of 5.7 years providing care to care recipients.
- Many reported that they spent an average of 75 hours a week providing care to care recipients. This translates to 10.6 hours a day of care to the care receivers.
- The care that caregivers provide ranges from providing 24 hours a day assistance or supervision to assisting in tasks, such as personal care (49%), paying for services (44%), home repair (34%), housekeeping (28%), financial management (17%), arrange for care (20%), and transportation (11%).

## *New York State Caregiver Services Survey: NY Connects Local Long Term Care Councils' Assessment of Caregiver Support Services:*

In 2008, a survey commissioned by the New York State Family Caregiver Council was designed and implemented by the Finger Lakes Geriatric Education Center (FLGEC) at the University of Rochester in conjunction with the NYSOFA. The purpose was to assess caregiver services in New York State and identify ways to be more responsive to the needs of caregivers in counties across the state.

### Key Findings:

- In general, the key informants are knowledgeable about the availability of most caregiver services in their communities. Those services with the most uncertainty are child guardianship, respite care for children of all ages, escort programs, companionship services, adult guardianship assistance, caregiver counseling and caregiver training.
- The key informants identified NY Connects as a valuable resource to provide information and assistance on long term care services. An in-depth look at the responses identified a need to promote awareness in all regions of the state on information about transportation/escort programs, adult guardianship assistance, respite care for children of all ages, and general legal services.
- When asked about service performance and barriers to caregiver services, the issue of cultural sensitivity in service availability and delivery was identified. For example, availability of bilingual staff and materials, and interpreters across nearly all caregiver services and supports were identified as gaps in the survey. This is an area where more attention and research should be directed.
- Availability of services outside usual business hours was identified as a need for several services including caregiver counseling, adult day health programs, social adult day programs, case management, home delivered meals, home rehabilitation and repairs services, information and assistance, general legal services, and transportation.
- Identified barriers to caregiver services across all categories of services were transportation, availability of staff, and resource limitations.

