

# 2008 CAREGIVER SURVEY RESULTS



COUNTY OF SUSSEX

DEPARTMENT OF  
HUMAN SERVICES

DIVISION OF SENIOR SERVICES

## **Introduction**

As Americans live longer and as the age span increases, there is a greater likelihood of a disability or dependence due to the onset of chronic medical conditions. As the elderly age in place, the need for assistance and supportive services will be provided by family members, mainly their children and other relatives, with some assistance from community-based programs. A caregiver is considered as someone who provides care for the physical and emotional needs of a family member or friend at home. Family members play an important role in the long-term care of the chronically ill and disabled older adults, with adult daughters or daughters-in-law making up the largest single group of these informal caregivers (Masrtire & Stephens, 2003). The number of individuals providing care to someone age 18 and over is growing. Gerontological authors are considering that caregiving is the most important aspect of family policy that needs attention, although it may not be the only hot topic at this time (Callahan, 2007). This can be attributed to the extensive media coverage about caregiving and the new realities of the aging workforce. In turn, many employers are aware that employees are often caregivers of aging parents (Timmermann, 2006).

Caregiving for elderly family members has become a major issue in the United States, not only for families, but also for employers. It is estimated that nearly two-thirds of caregivers work outside of the home and 30% of the workforce has some responsibility for a relative. That number is expected to increase to 54% by 2008 (as cited National Alliance for Caregiving, 2004). This trend is also prevalent in Sussex County, New Jersey.

## **Methodology**

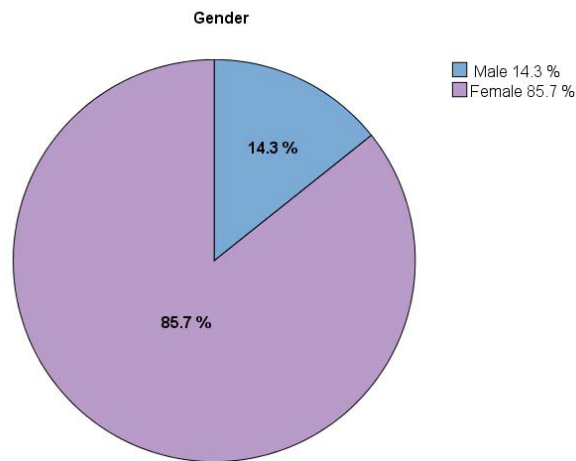
The Sussex County Division of Senior Services initiated a caregiver survey in October 2007 to identify the needs and circumstances of caregivers in Sussex County. The surveys were available to caregivers over three month period. Approximately 400 copies of the survey were distributed throughout the County via providers of elder care services, senior groups, nutrition sites, and other groups of seniors receiving services under the Older Americans Act. The survey was also distributed at various events during that period including a Senior Healthy Living Festival, two caregiver programs sponsored by the Division of Senior Services in conjunction with the Alzheimer's Association and

other events. The survey was available on the Sussex County website and was advertised on a local radio station.

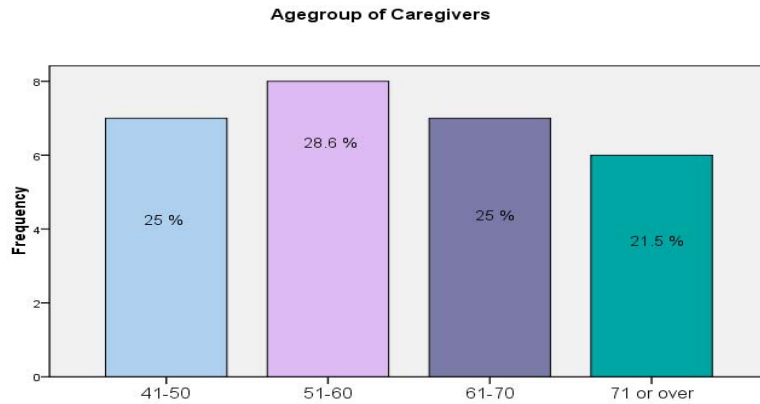
The survey consisted of twenty-four questions which requested the caregiver's age, gender, marital status, relationship to the care recipient, employment status and several questions regarding the total number of hours spent within the last week providing care in a variety of areas such as personal care, legal assistance, meal preparation, etc. The response rate for the survey was approximately 10% (37 responses), with nine completed surveys coming from the web site.

### The Responses to the Questions

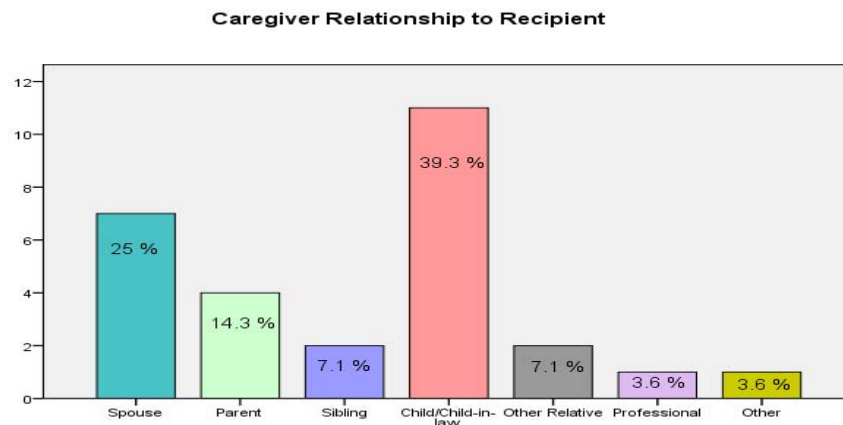
The majority of the responses 32 (85.7%) came from women who are caregivers. Their age range was from 41-50, which is considered the norm for caregivers.



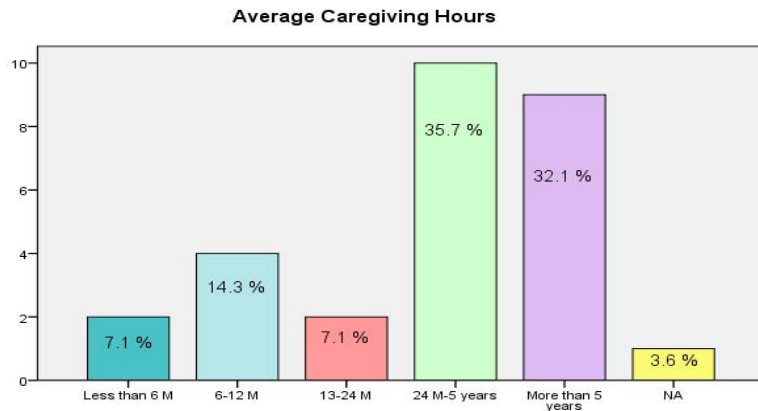
The average caregiver is a 46-year-old female “baby boomer,” with some college education, who works and spends more than 20 hours per week caring for a parent or parent-in law who lives nearby, although the percentage of male caregivers is increasing (as cited National Alliance for Caregiving, 2004). AARP (2008) reports that 45% of today’s working caregivers are men. Trends are also showing that men are assuming more responsibility when it comes to caregiving with 13.5 % or 5 of the respondents from the survey being men. The respondents to the Sussex County caregiver’s survey are basically consistent with the norm of caregivers nationwide with 34.14% or 13 respondents within the age group of 41-50, with 62.16% or 23 respondents caring for a parent or parent-in law.



Caregivers caring for a spouse were comprised of 18.92% or 7 respondents.



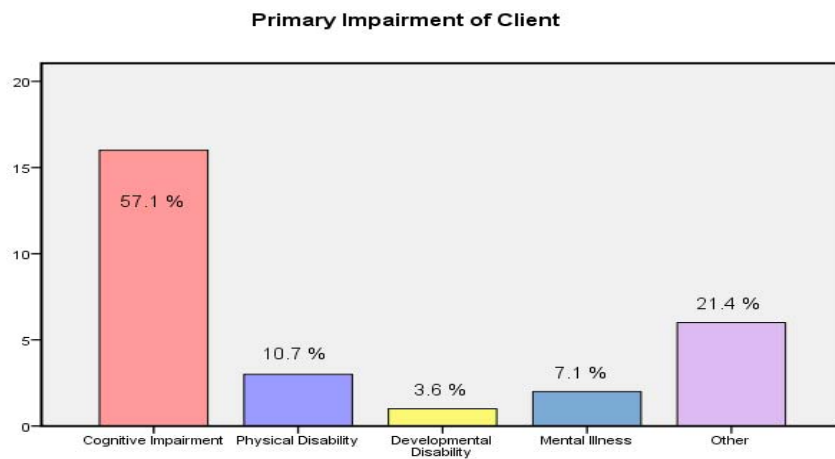
The average length of time that a caregiver had been caring for the recipient was in the range of 24 months to five years which was 37.84% or 14 respondents. The second highest time range being more than five years with 32.43% or 12 respondents. Only two respondents have been providing care for less than six months. The employment status of the caregivers was also explored with 48.65% or 18 respondents working full-time outside of the home; 21.4% or 7 respondents working part-time outside of the home, with the remaining 16.22% or 6 respondents being unemployed or retired.



The next four questions pertained to the total hours that the caregiver assisted the care recipient with such tasks as eating, bathing, dressing, toileting, meal preparation, laundry, light housekeeping, transportation to doctors appointments and/or shopping, legal matters, banking or other money matters. On an average, each area of assistance required 7-15 hours of support, with the highest amount of assistance needed for transportation to appointments and shopping. The lowest amount of assistance needed was in the area of banking and money management, requiring an average of one-two hours weekly. Care is provided in a variety of settings including the caregiver’s home, the recipient’s home or assisted living facilities. A majority of the care (64.86% or 24 responses) for the recipients is provided in the caregiver’s home, while 29.73% or 11 respondents provide care in the recipient’s home or apartment. The remainder of the care is provided in assisted living facilities.

The next ten questions on the survey pertained to whether the caregiver or care recipient needed help with personal care, transportation services, personal finances, adult day care, meal preparation, housekeeping, shopping, errands, case management, respite services, caregiver support or other services. In most cases (over 50%), support and assistance was needed for many of the services. Most of the support was needed in the areas of personal care, transportation, day care, housekeeping, shopping, errands, respite services and supports groups. Over 50% did not need assistance with meal preparation, case management or other services.

The final question on the survey requested what the impairment was that required the recipient to receive care from the caregiver. A majority (54.05% or 20 respondents) of the recipients were suffering from a cognitive impairment which consisted of Dementia, Alzheimer’s disease, Parkinson’s disease, Pick’s disease, Huntington’s Chorea, Strokes, Traumatic Brain Injury, etc. The second highest condition with 21.62% or 8 respondents was due to a physical disability. Finally, 45.95% or 17 of the respondents requested that the Division of Senior Services contact them to provide additional assistance in providing care.



### **What Community Resources Are Available in Sussex County?**

Sussex County has a variety of community resources that can assist seniors and/or caregivers in coping with related issues. The Sussex County Division of Senior Services is available to provide information and assistance to over 22,000 seniors age 60+ and/or their caregivers. The Division also presents educational programs to clubs, community organizations, church groups and employees of local businesses and corporations regarding caregiver issues and solutions.

As an Area Agency on Aging, the Sussex County Division of Senior Services is responsible for prioritizing needs and appropriately allocating federal, state and county funds for services that support those ages 60+ and their caregivers so that seniors can remain as independent as possible in their homes and avoid institutionalization. Transportation and assisted transportation services enables seniors to get to the doctors, shopping or to a congregate nutrition site. Legal services assist clients with a variety of

matters including power of attorneys; Do Not Resuscitate (DNR) orders and guardianship issues. An Adult Day Center provides care for clients when caregivers are employed or in need of support. The services of a Home Health Aide or Housekeeper can be utilized to provide additional supportive services to the client in the home. Home delivered meals are also available for the homebound that do not have someone to see to this need. Other caregiver support programs include support groups and a new program, “In Good Company,” that is scheduled to start in the Fall of 2008. This “drop-in” program, scheduled for specified hours each week, will provide supervised activities for care recipients, thus offering caregivers some respite and time to attend to their own personal needs. There is also a Statewide Respite Program available to provide short term relief for caregivers who need to take a short break or vacation.

The Division of Senior Services also provides information and assistance with prescription costs, Medicare, heating assistance, rental assistance and income tax assistance, along with other support services as needed. The Sussex County Division of Senior Services is located at One Spring Street in Newton. Office hours are 8:30 a.m. – 4:30 p.m., Monday to Friday. Information and resources can also be accessed at the Division’s website: [www.sussex.nj.us/seniorservices](http://www.sussex.nj.us/seniorservices)

### **Summary**

The results from this survey indicate that Sussex County is consistent with the national trends of caregiving and the issues associated with them. Most of the caregivers are females with the number of male caregivers increasing. The largest percentage of caregiving is assumed by the children of those in need, many of whom are working full or part time outside of their home, while raising their own families. The work of family caregiver for the elderly population goes far beyond what has been previously recognized as the care in the home compared to that received in healthcare facilities. Family caregivers, often untrained, unsupported and unseen, constitute a “shadow workforce” by acting as geriatric case managers, medical record keepers, paramedics and patient advocates that fill dangerous gaps in an uncoordinated, fragmented, bureaucratic and often depersonalized system (Bookman & Harrington, 2007).

Employed caregivers are more likely to use caregiver support services compared to non-employed caregivers (Scharlach, Gustavson & Dal Santo, 2007). Home and community based care allows the elderly to continue to function as independent members of society. Scharlach, et al. (2007) concludes that reduced amounts of care by caregivers who are employed full time appear to be offset by increased assistance from other informal and formal sources. However employed caregivers continue to be involved in the entire range of caregiving tasks. An overall trend finds caregivers utilizing a combination of informal and formal sources of assistance in caring for their loved ones. However, social, cultural and economic factors impact the actual engagement of support services (Scharlach, et al., 2007).

Programs that include home and community-based care are increasing in need, which is replacing nursing home care that is very costly to both the individual and government based programs which supplement these services. These issues potentially affect everyone, whether one is the individual in need, the caregiver, or the taxpayer. According to the Center for Medicare and Medicaid Services, about 60 percent of people over 65 will need some type of long term care assistance during their lifetime.

The passage of the Older Americans Act Amendments of 2000 established the *National Family Caregivers Support Program* by originally appropriating \$125 million to provide much needed relief for caregivers. However, the program also broadens the scope of caregivers to include grandparents caring for grandchildren living with them. In fiscal year 2007, the appropriation increased to \$162 million. All fifty states have instituted the program, through the local Area Agencies on Aging, with the intent to provide resources directly to caregivers, but the demarcation of the programs may be difficult to achieve due to the differing care programs in all states, along with the lack of clarity within the states (Callahan, 2007). Some of the allowable services under this Caregiver Support Program include information and assistance, assistance to access services, individual counseling through support groups and caregiver training, respite care and supplemental services which can include home modifications, assistive technologies, emergency response systems, equipment, incontinence supplies, transportation, or whatever a caregiver needs. Additional or new funding by the federal or state governments would enable the promotion and maintenance of current programs and



services, along with providing additional options for caregivers. The financial eligibility for the programs should be expanded to include and support middle-income caregivers.

Sussex County Division of Senior Services is taking an active role in developing and implementing programs and services to provide relief and support to the client and/or the caregiver. Expanding and coordinating these services to meet the ever-changing needs of the client and/or caregiver is a challenge that will continue for years to come.

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