

INFORMAL CAREGIVING: IMPLICATIONS FOR PUBLIC HEALTH

What is informal caregiving?

Informal caregiving refers to the help and support family members and friends provide daily to individuals who are either temporarily or permanently unable to function independently. Caregiving involves a range of activities, such as assisting with personal hygiene, helping with medication and doctor's visits, managing finances, acting as a patient advocate, and providing emotional support. While informal caregivers often have a long-term commitment to the person(s) they are helping, they usually are not paid for their efforts or trained for the tasks they perform.

What is the economic impact of caregiving?

In 2004, an estimated 44.4 million Americans age 18 or older provided unpaid care to another adult in the preceding 12 months.¹ Informal caregivers provide about 80% of all long-term care services in the country. Shorter hospital stays and increased usage of outpatient procedures - changes that have increased the efficiency of medical care - have shifted responsibility from formal caregivers towards informal caregivers.

If paid for, informal care would cost \$375 billion per year, an amount more than all federal and state Medicaid spending in 2007 and approximately 2.7% of the US total GDP for that year.² This does not include the \$17.1 billion annual cost of informal caregiving in terms of lost productivity to US businesses due to workplace disruptions, scheduled and unscheduled absences, leave of absences, reduction from full-time to part-time work, opting for early retirement, and leaving work entirely to be a caregiver.³ As the baby boomer generation (those born between 1946 and 1964) ages, the need for informal care, and the associated costs to the US economy, will likely increase.

Who are the caregivers in LA County?

The 2007 Los Angeles County Health Survey (LACHS) inquired about adult caregiving, prefacing the set of questions with the following: "People may provide regular care or help to another adult who is aging or has a long-term illness or disability. This person may be someone who lives with you or lives somewhere else." Then, respondents were asked: "During the past month, did you provide any such care or assistance to an adult who is aging or has a long-term illness or disability?"

- An estimated 16.3% of adults, or 1.2 million people, reported being informal caregivers (Table 1).
- The percentage of adults who reported caregiving was higher among those 40-64 years compared to those 18-39 years and 65 years or over.
- Asians/Pacific Islanders reported the highest rates of being a caregiver (19.9%), followed by African Americans (17.3%), whites (16.3%), and Latinos (14.7%).
- The San Gabriel and San Fernando Service Planning Areas (SPAs) reported the highest rates of caregiving (17.6% and 17.3%, respectively), while the West SPA reported the lowest rate of caregiving (13.9%).

To whom are these caregivers providing care?

An adult can provide care to another adult in many different situations. The relationship between the caregiver and carereceiver (e.g., spouse, parent, other family member, or friend) and the type of

1. National Alliance for Caregiving & AARP. (2004). *Caregiving in the U.S.* Washington, DC.
2. National Family Caregivers Association. *Principles, Plans, and Policy Recommendations, 2008-2009* (Revised December 9, 2008); Kensington, MD.
3. Family Caregiver Alliance, *2009 National Policy Statement*. San Francisco, CA; http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2313.



1 Percent of Adults who Reported Being Caregivers, 2007

TABLE

	Percent (%)	95% CI	Est #
Los Angeles County	16.3	15.2-17.4	1,205,000
Gender			
Male	16.0	14.4-17.6	581,000
Female	16.6	15.2-18.0	624,000
Age Group			
18-24	16.4	12.4-20.3	141,000
25-29	12.7	8.3-17.0	105,000
30-39	11.9	9.7-14.0	188,000
40-49	19.8	17.4-22.1	303,000
50-59	21.3	18.8-23.8	228,000
60-64	18.4	15.2-21.6	87,000
65 and over	14.8	12.8-16.7	153,000
Race/Ethnicity			
Latino	14.7	13.1-16.3	456,000
White	16.3	14.7-18.0	413,000
African-American	17.3	13.6-20.9	113,000
Asian/Pacific Islander	19.9	16.2-23.6	193,000
Federal Poverty Level [§]			
0-99% FPL	14.0	11.9-16.2	256,000
100-199% FPL	17.8	15.4-20.3	283,000
200%-299% FPL	16.4	13.8-19.0	166,000
300% or above FPL	16.9	15.2-18.6	500,000
Service Planning Area			
Antelope Valley	15.8	12.3-19.3	38,000
San Fernando	17.3	14.9-19.7	270,000
San Gabriel	17.6	15.2-20.1	242,000
Metro	14.9	12.1-17.7	138,000
West	13.9	10.5-17.3	73,000
South	15.6	11.8-19.4	105,000
East	15.7	13.0-18.5	149,000
South Bay	16.6	13.5-19.8	190,000

[§] Based on U.S. Census 2006 Federal Poverty Level (FPL) thresholds which for a family of four (2 adults, 2 dependents) correspond to annual incomes of \$20,444 (100% FPL), \$40,888 (200% FPL) and \$61,332 (300% FPL). These thresholds were the values at the time of survey interviewing.

condition that has precipitated the need for care can impact the amount of time spent caregiving and the level of care necessary.

- The majority of caregivers (78.1%) reported caring for one other adult (Table 2).

2 Caregiver-Carereceiver Characteristics, 2007

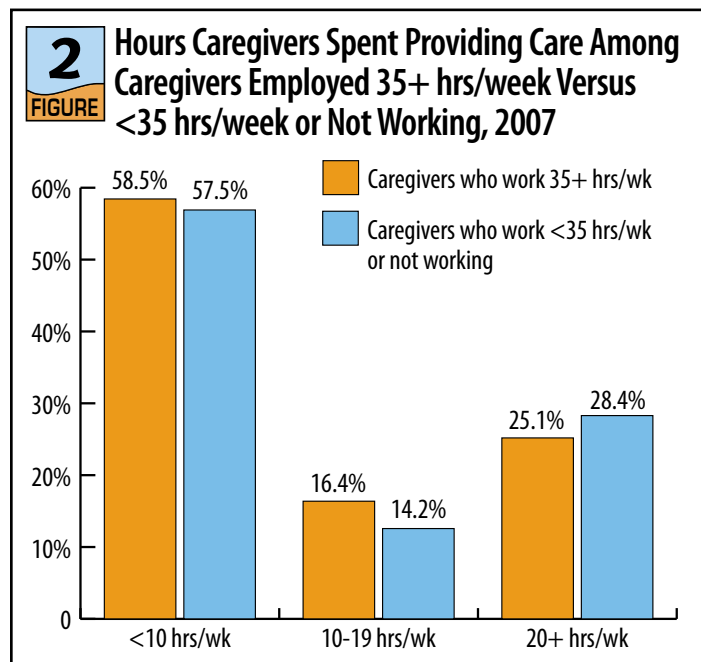
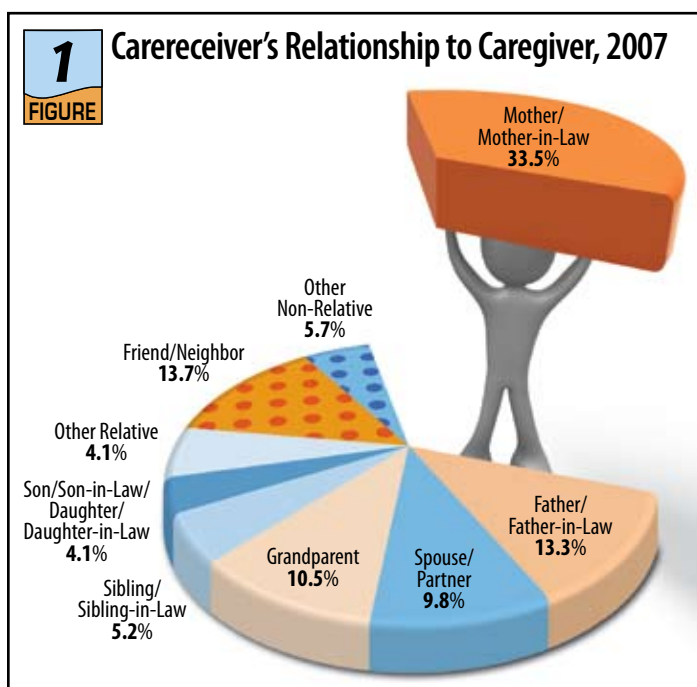
TABLE

Age Group of Carereceiver	Percent (%)	95% CI	Est #
18-49	13.6	11.0-16.2	157,000
50-64	19.1	15.7-22.4	221,000
65 and over	67.3	63.6-71.1	779,000
Relationship with Carereceiver			
Mother/Mother-in-Law	33.5	30.3-36.8	404,000
Father/Father-in-Law	13.3	10.4-16.1	160,000
Spouse/Partner	9.8	8.1-11.6	119,000
Grandparent	10.5	7.9-13.1	127,000
Sibling/Sibling-in-Law	5.2	3.5-7.0	63,000
Son/Son-in-Law/ Daughter/Daughter-in-Law	4.1	2.8-5.3	49,000
Other Relative	4.1	2.8-5.4	49,000
Friend/Neighbor	13.7	11.4-16.0	166,000
Other Non-Relative	5.7	4.1-7.3	69,000
# of Carereceivers Caregiver Cares For			
1	78.1	75.2-80.9	933,000
2	16.9	14.2-19.6	202,000
3 or More	5.0	3.7-6.3	60,000
Other Characteristics of Carereceiver			
Lives with Caregiver	33.2	30.0-36.5	398,000
Problems with Memory Loss or Alzheimer's Disease	24.1	21.2-27.0	285,000
Dependent on Assistance for 2+ ADLs (Activities of Daily Living)	45.7	42.1-49.3	545,000

- More than two-thirds (67.3%) of those who reported being caregivers cared for someone who was 65 years of age or older; 19.1% reported caring for someone 50-64 years; and 13.6% reported caring for someone 18-49 years.

- Most caregivers (80.5%) reported having a familial relationship with those for whom they were caring. One-third (33.5%) of informal caregivers reported caring for their mother or mother-in-law (Figure 1).

less than 35 hours per week or who were not in the labor force, one-quarter (25.1%) of those who work full time also spent 20 or more hours per week providing care (Figure 2).



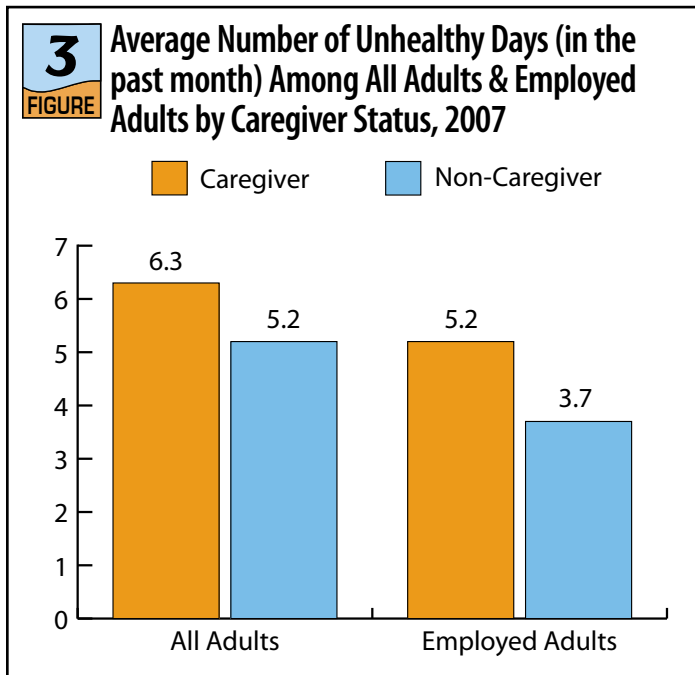
- One-third (33.2%) of caregivers reported living with the person for whom they were caring.
- Almost one-quarter (24.1%) of caregivers reported caring for an adult who has problems with memory loss or a disorder like Alzheimer's disease.
- Nearly half (45.7%) of caregivers reported that the person being cared for was dependent on them for assistance with two or more of the following activities of daily living (ADLs): transportation, eating, toileting, bathing, dressing, or taking medication.
- Most caregivers (57.8%) reported spending less than 10 hours per week giving care, while 15.1% spent 10-19 hours, and 27.1% spent 20 or more hours.
- Although the amount of time spent caregiving was similar for caregivers working 35 or more hours per week (full time) and those working

What is the health status of caregivers?

Caregiving is an important public health issue, in part, because of what is considered the 'caregiver burden.' This is defined as the state of physical, emotional, and mental exhaustion resulting from the intense demands of caregiving. A major contribution to the physical and emotional toll of caregiving is that many caregivers do not identify themselves as such, and typically do not seek assistance for themselves. This can lead to the caregivers becoming isolated, frustrated, and tired, which can put added strain on their health. Results from the 2007 LACHS found the following:

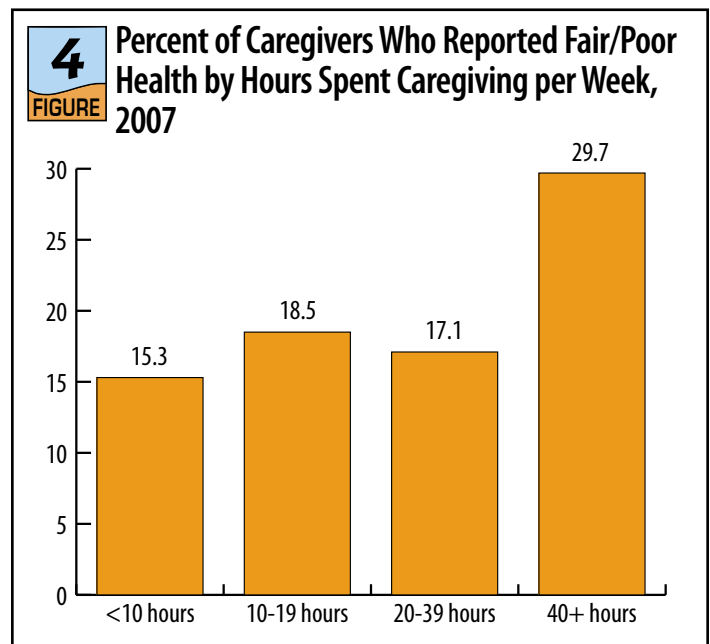
- A higher percentage of caregivers (53.1%) reported having one or more of the following chronic conditions than non-caregivers (48.6%): hypertension, high cholesterol, diabetes, heart disease, and depression.
- Caregivers reported more unhealthy days in the past month (6.3) compared to non-caregivers (5.2).

- Employed caregivers reported nearly 1½ times the number of unhealthy days in the past month (5.2) compared to employed non-caregivers (3.7) (Figure 3).



- Caregivers who provided 40 or more hours of care per week were much more likely to report fair or poor self-perceived health (29.7%) than did caregivers who provided less than 10 hours of care per week (15.3%) (Figure 4).

According to a 2004 report by the National Alliance for Caregiving and AARP,⁴ the most frequently reported unmet needs of caregivers in the US were finding time for themselves (35%), managing emotional and physical stress (29%), and balancing work and family responsibilities (29%). About 3 in 10 caregivers reported they needed help keeping the person they care for safe (30%) and finding easy activities to do with the person they care for (27%). One in five caregivers said they needed help talking with doctors and other healthcare professionals (22%) or making end-of-life decisions (20%).



What can be done?

What can individuals and families do?

Concerns over nursing home placement and soaring costs of long-term care are contributing to more individuals falling into the caregiver role. Often, even caregivers fail to recognize themselves in this role, therefore it is not unusual for caregivers to take on more than they can realistically handle. This can be compounded by feelings of guilt about asking for help. Additionally, caregivers often underestimate the time required for caregiving as well as its impact on their ability to work. Recognizing the impact of caregiving, being open to solutions, understanding that seeking help is reasonable, and that there are others also in similar predicaments (i.e., that the caregiver is not alone), can ease the burden on the caregiver. Some caregivers may take solace in knowing that many others share their situation (see “**IF YOU ARE A CAREGIVER**”).

IF YOU ARE A CAREGIVER

- Do not be afraid to ask for help (see [on the web](#) for available resources)
- Participate in support groups
- Take care of yourself
- Obtain further caregiving training
- Call your local senior center or Area Agency on Aging to assist in locating respite care services in your area
- Take advantage of community resources such as Meals on Wheels and adult day care programs
- Get help with financial and legal planning to assure the care recipient has a designated Power of Attorney for health care and Durable Power of Attorney for finances

What can communities, health professionals, and local agencies do?

Federal, state and local agencies as well as community-based organizations and employers can assist in reducing caregiver stress by:

- Promoting awareness and educating the public about the health and financial consequences of being a caregiver
- Increasing access and availability of caregiver education and support programs
- Developing primary care interventions that identify patients as caregivers, address their needs, and link them with support services
- Raising awareness among health professionals about the need for detecting signs of psychological distress or depression among their patients who are caregivers and making sure appropriate mental health services are available



on the web



Partners in Care Foundation is a non-profit center of innovation whose mission is to change the shape of health care. The Foundation pursues its mission through programs such as the Family Care Partnership, a network of experts working together, focusing on addressing the complex challenges faced by caregivers, seniors, veterans and adults with disabilities. www.picf.org

The Los Angeles Caregiver Resource Center (LACRC) is part of a statewide system established by the California Department of Mental Health, and consists of 11 non-profit CRCs all dedicated to the assistance and support of caregivers and their families.

www.losangelescrc.org; www.cacrc.org

The National Family Caregivers Association (NFCA) is a grassroots organization that empowers family caregivers to take actions that will improve their life and the life of the recipient by providing them with education, support, and a public voice. NFCA's core Caring Every Day messages are: Believe in Yourself. Protect Your Health. Reach Out for Help. Speak Up for Your Rights.

www.thefamilycaregiver.org

The mission of the **City of Los Angeles Department of Aging** is to improve the older population's quality of life, independence, health and dignity by managing community based senior programs that are comprehensive, coordinated and accessible, and to advocate for the needs of older citizens.

<http://aging.lacity.org/caregivers/family.cfm>

The **Los Angeles County Department of Community and Senior Services** provides a variety of resources through many diverse programs from Family Caregiver to Community Centers, Elder Care, and Legal Services.

<http://css.lacounty.gov/Aaa/Eldercare.html>

The **Alzheimer's Association** has information and resources for choosing caregivers. www.alz.org/living_with_alzheimers_choosing_care_providers.asp

Established in 1996, the **National Alliance for Caregiving (NAC)** is a nonprofit coalition of nearly 40 national organizations that was created to conduct research, do policy analysis, develop national programs for caregivers, and increase public awareness of caregiving issues. www.caregiving.org

What can policymakers do?

Policy recommendations should address the financial burden as well as the emotional and mental stresses that are placed on caregivers. National and local policies for caregivers that should be considered include:

- Employer policies that allow flexible work hours and telecommuting options
- Tax credits and wage replacement at the federal level, and incentives for states that include job protection for workers who leave to be caregivers
- Work credits to the Social Security system for those who leave to become caregivers; this would aid retirement benefits of the caregiver and keep them out of poverty
- Extension of California Paid Family Leave to include siblings and grandparents

- Expansion of the Family and Medical Leave Act (FMLA) to include domestic partners, siblings, in-laws, and/or grandparents
- Improved access to affordable, high quality respite care as part of the supportive services network
- Appropriate, timely, and on-going education and training for caregivers in order to meet their caregiving responsibilities
- Affordable, high quality, comprehensive services coordinated across all care settings

As the LA County population ages, more adults will fall into the informal caregiver role. Policymakers, communities, health care professionals, government agencies, and businesses can help in improving caregivers' health, quality of life, and social circumstances by promoting or implementing these recommended strategies.

The Los Angeles County Health Survey is a periodic, population-based telephone survey that collects information on sociodemographic characteristics, health status, health behaviors, and access to health services among adults and children in the county. The 2007 survey collected information on a random sample of 7,200 adults and 5,728 children. The survey was conducted for the Los Angeles County Department of Public Health by Field Research Corporation and was supported by grants from First 5 LA, the Tobacco Control and Prevention Program, the Emergency Response and Bioterrorism Preparedness Program and various Department of Public Health programs.

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For additional information about the L.A. County Health Survey, visit: www.publichealth.lacounty.gov/ha



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