



## **Fact Sheet:**

# **Selected Long-Term Care Statistics**

### **What is long-term care?**

Individuals need long-term care when a chronic condition, trauma, or illness limits their ability to carry out basic self-care tasks, called *activities of daily living* (ADLs), (such as bathing, dressing or eating), or *instrumental activities of daily living* (IADLs) (such as household chores, meal preparation, or managing money). Long-term care often involves the most intimate aspects of people's lives—what and when they eat, personal hygiene, getting dressed, using the bathroom. Other less severe long-term care needs may involve household tasks such as preparing meals or using the telephone.

A report prepared by the U.S. Senate Special Committee on Aging (February, 2000) described long-term care as follows:

*It [long-term care] differs from other types of health care in that the goal of long-term care is not to cure an illness, but to allow an individual to attain and maintain an optimal level of functioning....Long-term care encompasses a wide array of medical, social, personal, and supportive and specialized housing services needed by individuals who have lost some capacity for self-care because of a chronic illness or disabling condition.<sup>1</sup>*

Because long-term care needs and services are wide-ranging and complex, statistics may vary from study to study. Sources for

the following information are cited at the conclusion of this fact sheet.

### **Who needs long-term care?**

- Annually 8,357,100 people receive support from the 5 main long-term care service; home health agencies (4,742,500), nursing homes (1,383,700), hospices (1,244,500), residential care communities (713,300) and adult day service centers (273,200).<sup>1</sup> [Updated February 2015]
- An estimated 12 million Americans needed long-term care in 2007.<sup>2</sup> [Updated February 2015]
- Most but not all persons in need of long-term care are elderly. Approximately 63% are persons aged 65 and older (6.3 million); the remaining 37% are 64 years of age and younger (3.7 million).<sup>3</sup>
- The lifetime probability of becoming disabled in at least two activities of daily living or of being cognitively impaired is 68% for people age 65 and older.<sup>4</sup>
- By 2050, the number of individuals using paid long-term care services in any setting (e.g., at home, residential care such as assisted living, or skilled nursing facilities) will likely double from the 13 million using services in 2000, to 27 million people. This estimate is

influenced by growth in the population of older people in need of care.<sup>5</sup>

- Of the older population with long-term care needs in the community, about 30% (1.5 million persons) have substantial long-term care needs (three or more ADL limitations). Of these, about 25% are 85 and older and 70% report they are in fair to poor health.<sup>6</sup>
- In 2012, 14.8% of the 65+ population were reported to be below the poverty level.<sup>7</sup> [Updated February 2015]
- Among the population aged 65+, 69% will develop disabilities before they die, and 35% will eventually enter a nursing home.<sup>8</sup> [Updated February 2015]
- Nearly a fifth of older people will incur more than \$25,000 in lifetime out-of-pocket long-term costs before they die.<sup>9</sup> [Updated February 2015]
- The prevalence of cognitive impairment among the older population increased over the past decade, while the prevalence of physical impairment remains unchanged.<sup>10</sup>
- In 2002, the percentage of older persons with moderate or severe memory impairment ranged from about 5% among persons aged 65–69 to about 32% among persons aged 85 or older.<sup>11</sup>
- Individuals 85 years and older, the oldest old, are one of the fastest growing segments of the population. In 2012, there are an estimated 5.9 million people 85+ in the United States.<sup>12</sup> [Updated February 2015] This figure is expected to increase to 19.4 million by 2050.<sup>13</sup> This means that there could be an increase from 1.6 million to 6.2 million people age 85 or over with severe or moderate memory impairment in 2050.<sup>14</sup>

## Where do People Receive Long-Term Care and from Whom?

### Family and Informal Caregivers

*Informal caregiver* and *family caregiver* are terms used to refer to unpaid individuals such as family members, partners, friends and neighbors who provide care. These persons can be primary (i.e. the person who spends the most time helping) or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. Formal caregivers are volunteers or paid care providers associated with a service system.<sup>15, 16</sup>

Estimates vary on the number of family and informal caregivers in the U.S., depending on the definitions used for both caregiver and care recipient as well as types of care provided.

- **65.7 million** informal and family caregivers provide care to someone who is ill, disabled or aging in the U.S.<sup>17</sup> [Updated February 2015]
- **52 million** caregivers (or one out of every five households ) are involved in caregiving to persons aged 18 or over.<sup>18</sup> [Updated February 2015]
- **43.5 million** caregivers provide care for someone aged 50+ and 14.9 million care for someone who has Alzheimer's or other Dementia.<sup>19</sup> [Updated February 2015]
- **27.3 million** family caregivers provide personal assistance to adults (aged 15+) with a disability or chronic illness.<sup>20</sup>
- **5.8<sup>21</sup> to 7<sup>22</sup> million** people (family, friends and neighbors) provide care to a person (65+) who needs assistance with everyday activities.<sup>23</sup>

- **8.9 million** informal caregivers provide care to someone aged 50+ with dementia.<sup>24</sup> By the year 2007, the number of caregiving households in the U.S. for persons aged 50+ could reach 39 million.<sup>25</sup>
- Two out of three (66%) of older people with disabilities who receive LTSS at home get *all* their care exclusively from their family caregiver, mostly wives and daughters. Another quarter (26%) receives some combination of family care and paid help; only 9% receive paid help alone.<sup>26</sup> [Updated February 2015]
- Even among the most severely disabled older persons living in the community, about two-thirds rely solely on family members and other informal help, often resulting in great strain for the family caregivers.<sup>27</sup>
- The use of informal care as the only type of assistance by older Americans aged 65 and over increased from 57% in 1994 to 66% in 1999. The growth in reliance upon informal care between 1994 and 1999 is accompanied by a decline in the use of a combination of informal and formal care from 36% in 1994 to 26% in 1999.<sup>28</sup>
- 30% of persons caring for elderly long-term care users were themselves aged 65 or over; another 15% were between the age of 45–54.<sup>29</sup>
- Lost income and benefits over a caregiver’s lifetime is estimated to range from a total of \$283,716 for men to \$324,044 for women, or an average of \$303,880.<sup>30</sup> [Updated February 2015]
- community, not in institutions.<sup>31</sup> [Updated February 2015]
- Elderly people with limitations in three or more ADL’s who live in the community receive an average of 9 hours of assistance per day (counting both formal and informal sources of care) and people age 85 or older with that degree of impairment typically receive about 11 hours of assistance per day.<sup>32, 33</sup> [Updated February 2015]
- The trend towards community-based services as opposed to nursing home placement was formalized with the Olmstead Decision (July, 1999)—a court case in which the Supreme Court upheld the right of individuals to receive care in the community as opposed to an institution whenever possible.
- The proportion of Americans aged 65 and over with disabilities who rely entirely on formal care for their personal assistance needs has increased to 9% in 1999 from 5% in 1984.<sup>34</sup>
- Between 2000 and 2002, the number of licensed assisted living and board and care facilities increased from 32,886 to 36,399 nationally, reflecting the trend towards community-based care as opposed to nursing homes.<sup>35</sup> Most assisted living facilities, however, are unlicensed.
- Most assisted living facilities (ALFs) discharge residents whose cognitive impairments become moderate or severe or who need help with transfers (e.g. moving from a wheelchair to a bed.) This limits the ability of these populations to find appropriate services outside of nursing homes or other institutions.<sup>36</sup>

### Home and Community-Based Care

- The vast majority—80%—of elderly people receiving assistance, including many with several functional limitations, live in private home in the

## Nursing Home Care

- Institutionalization is much more common at older ages; in 2010, about one in eight people age 85 or older (13 percent) resided in institutions, compared with 1 percent of people ages 65 to 74.<sup>37</sup>[Updated February 2015]
- In 2012, there were 1.4 million people in nursing homes nationally<sup>38</sup> [Updated February 2015]
- Between 2002 and 2012, private-pay prices for a private or semiprivate room in a nursing home grew by an average of 4.0 percent and 4.5 percent, respectively, per year.<sup>39</sup>[Updated February 2015]
- Of the population aged 65 and over in 1999, 52% of the nursing home population was aged 85 or older compared to 35% aged 75–84, and 13% aged 65–74.<sup>40</sup>
- Between 1985 and 1999, the number of adults 65 and older living in nursing homes increased from 1.3 million to 1.5 million. In 1999, almost three-quarters (1.1 million) of these older residents were women.<sup>41</sup>

## Long-Term Care Expenditures

- In 2012, total spending (public, out-of-pocket and other private spending) for long-term care was \$219.9 billion, or 9.3% of all U.S. personal health care spending. This is projected to increase to \$346 billion in 2040.<sup>42</sup>[Updated February 2015]
- In 2010, approximately 45% of Medicaid long-term care funding was spent on HCBS. About 55% was directed toward institutional long-term care, which includes nursing homes and intermediate care facilities for people with developmental disabilities, and mental health facility services.<sup>43</sup> [Updated February 2015]

- Caregiver services were valued at \$450 billion per year in 2009- up from \$375 billion in year 2007.<sup>44</sup> [Updated February 2015]
- Despite the trend toward community-based care as opposed to institutionalized care, only 18.2% of long-term care expenditures for the elderly are for community-based care.<sup>45</sup>
- In 2002, 16.4 billion Medicaid dollars were spent for home and community-based services within long-term care. This figure has increased at a 25% rate annually since 1990.<sup>46</sup>
- Expenditures for skilled nursing facility (SNF) care are much greater than care provided in other settings. Average expenses per older adult in a skilled nursing facility can be four times greater than average expenditures for that individual receiving paid care in the community.<sup>47</sup>
- In 2003, Medicaid paid \$83.8 billion dollars for long-term care services, roughly one-third of all Medicaid spending. 27.8 billion of these dollars were spent on community-based long-term care services. Home and community-based (HCBS) waivers accounted for roughly two-thirds of community-based long-term care expenditures.<sup>48</sup>
- In 2000, spending for older adults aged 65 or older accounted for 57% of Medicaid dollars, with the remaining 43% spent on those under age 65.<sup>49</sup>
- 31.9% of the annual estimated home care expenditures were paid for by Medicare in 2003, a little over 18% were paid for out-of-pocket or by private insurance,

and approximately 13% were covered by Medicaid.<sup>50</sup>

- Only 7% of residents receive Medicaid coverage for assisted living.<sup>51</sup>
- Studies have shown that the delivery of home or community-based long-term care services is a cost-effective alternative to nursing homes. Care in the home or community—not nursing home care—is what most Americans would prefer.<sup>52,53</sup>
  - In 2004, the average daily rate for a private room in a skilled nursing facility was \$192 for a private room or \$70,080 annually, and \$169 or \$61,685 annually for a semi-private room. The hourly rate for a home health aide was \$18.12.<sup>54</sup>
  - In 2000, annual cost estimates were \$13,000 for adult day care and \$25,300 for assisted living.<sup>55</sup>
- Over two-thirds of the current health care dollar goes to treating chronic illness; for older persons the proportion rises to almost 95%.<sup>56</sup>
- The aging of the population, especially those 85+—the most in need of long-term care—is expected to result in a tripling of long-term care expenditures, projected to climb from \$115 billion in 1997 to \$346 billion (adjusted for inflation) annually in 2040.<sup>57</sup>
- One if four people age 45 and over are not at all prepared financially if they suddenly required long-term care for an indefinite period of time.<sup>58</sup> [Updated February 2015]

## Future Issues

- Research suggests that if savings rates are not increased and government programs to assist the

elderly are not strengthened, many retirees will face serious problems attaining needed health and long-term care services in the future. By 2030, many retirees will not have enough income and assets to cover basic expenditures or any expenses related to a nursing home stay or services from a home health provider.<sup>59</sup>

- Shorter hospital stays and increased usage of outpatient procedures—changes that have increased the effectiveness of medical care—have shifted responsibility toward unpaid providers of care from paid providers, increasing burdens on family caregivers.<sup>60</sup>

## Notes

<sup>1</sup> Special Committee on Aging. *Developments in Aging: 1997 and 1998, Volume 1, Report 106-229*. Washington, DC: United States Senate, 2000.

<sup>2</sup> Rogers, S., & H. Komisar. *Who needs long-term care? Fact Sheet, Long-Term Care Financing Project*. Washington, DC: Georgetown University Press, 2003.

<sup>3</sup> *Ibid.*

<sup>4</sup> AARP. *Beyond 50.2003: A Report to the Nation on Independent Living and Disability, 2003*, <<http://www.aarp.org/research/health/disabilities/aresearch-import-753.html>> (11 Jan 2005).

<sup>5</sup> U.S. Department of Health and Human Services, and U.S. Department of Labor. *The future supply of long-term care workers in relation to the aging baby boom generation: Report to Congress*. Washington, DC: Office of the Assistant Secretary for Planning and Evaluation, (2003).

<<http://aspe.hhs.gov/daltcp/reports/ltcwork.htm>> (20 Jan 2005)

<sup>6</sup> The Henry J. Kaiser Foundation. *Long-term Care: Medicaid's role and challenges* [Publication #2172].

Washington, DC: Author, 1999.

<sup>7</sup> Ibid.

<sup>8</sup> U.S. Department of Health and Human Services. The Characteristics of Long-term Care Users. Rockville: Agency for Healthcare Research and Quality, 2001.

<sup>9</sup> Ibid.

<sup>10</sup> Ibid.

<sup>11</sup> Federal Interagency Forum on Aging-Related Statistics. Older Americans 2004: Key indicators of well-being, Federal Interagency Forum on Aging-Related Statistics. Washington, DC: U.S. Government Printing Office, 2004.

<sup>12</sup> U.S. Census Bureau. Statistical Abstract of the United States: 2000. Washington, DC: U.S. Census Bureau, 2000, <<http://www.census.gov/prod/2004pubs/04statab/pop.pdf>> (11 Jan 2005)

<sup>13</sup> Ibid.

<sup>14</sup> The number is extrapolated by applying projected population estimates in 2050 to prevalence estimates of moderate to severe memory impairments in 2002.

<sup>15</sup> Fradkin, L.G., and A. Heath. Caregiving of older adults. Santa Barbara, CA: ABC-CLIO, Inc., 1992.

<sup>16</sup> McConnell, S., J.A. Riggs. A public policy agenda: Supporting family caregiving, in M. A. Cantor (Ed.) Family Caregiving: Agenda for the Future. San Francisco: American Society on Aging, 1994.

<sup>17</sup> Health and Human Services. Informal caregiving: Compassion in action. Washington, DC: Author, 1998. Based on data from the 1987/1988 National Survey of Families and Households (NSFH), 2002.

<sup>18</sup> National Alliance for Caregiving and AARP. Caregiving in the U.S. Washington, DC: Author, 2004.

<sup>19</sup> Ibid.

<sup>20</sup> Arno, P. S., Well Being of Caregivers: The Economic Issues of Caregivers, in T. McRae (Chair), New Caregiver Research. Symposium conducted at the annual meeting of the American Association of Geriatric Psychiatry. Orlando, FL. Data from 1987/1988 National Survey of Families and Households (NSFH), 2002.

<sup>21</sup> Spector, W. D. et al. The characteristics of

long-term care users (AHRQ Publication No. 00-0049). Rockville: Agency for Healthcare Research and Policy, 2000.

<sup>22</sup> See note 17 above.

<sup>23</sup> Both of these reports used data from 1994 National Long-Term Care Survey. The Health and Human Services report also incorporated data from the 1982 National Long-Term Care Survey and the Informal Caregiver Supplement to the 1989 National Long-Term Care Survey.

<sup>24</sup> Alzheimer's Association and National Alliance for Caregiving. Families care: Alzheimer's caregiving in the United States 2004. Washington, DC: Author, 2004.

<sup>25</sup> National Alliance for Caregiving and AARP. Family caregiving in the U.S.: Findings from a national survey. Washington, DC: Author, 1997.

<sup>26</sup> Thompson, L. Long-term care: Support for family caregivers [Issue Brief]. Washington, DC: Georgetown University, 2004. Long-Term Care Financing Project.

<sup>27</sup> Ibid. Data based on analysis of data from the 1994 and 1995 National Health Interview Surveys on Disability by Health Policy Institute, Georgetown University.

<sup>28</sup> See note 11 above.

<sup>29</sup> See note 8 above.

<sup>30</sup> Stucki, B. R., and J. Mulver. Can aging baby boomers avoid the nursing home? Long-term care Insurance for Aging in Place. Washington, DC: American Council of Life Insurers, 2000.

<sup>31</sup> Agency for Healthcare Research and Quality. Long-term Care users range in age and most do not live in nursing homes: Research alert. Rockville: Author, 2000.

<sup>32</sup> LaPlante, M.P., C. Harrington, and T. Kang. 2002. Estimating paid and unpaid hours of personal assistance services in activities of daily living provided to adults living at home. Home Services Research 327(2), 397-415.

<sup>33</sup> Ibid.

<sup>34</sup> See note 11 above.

<sup>35</sup> Mollica, R. State Assisted Living Policy: 2002. Portland: National Academy

for State Health Policy, 2002.

<sup>36</sup> Hawes, R. M., & C.D. Phillips. A National Study of Assisted Living for the Frail Elderly: Results of a national survey of facilities. Beachwood: Myers Research Institute, 1999.

<sup>37</sup> Gabrel, C. S. Characteristics of Elderly Nursing Home Current Residents and Discharges: Data from the 1997 National Nursing Home Survey [Advance Data from Vital and Health Statistics; No. 312]. Hyattsville: National Center for Health Statistics, 2000.

<sup>38</sup> National Center for Health Statistics. Health, United States, 2004. Hyattsville: U.S. Department of Health and Human Services, 2004.

<sup>39</sup> See note 11 above.

<sup>40</sup> National Center for Health Statistics. Health, United States, 2000. Hyattsville: U.S. Department of Health and Human Services, 2000.

<sup>41</sup> See note 11 above.

<sup>42</sup> Komisar, H. & L. Thompson. Who Pays for Long-Term Care? Fact Sheet, Long-Term Care Financing Project. Washington, DC: Georgetown University Press, 2004.

<sup>43</sup> Ibid.

<sup>44</sup> See note 20 above.

<sup>45</sup> Doty, P. Cost-effectiveness of Home and Community-based Long-term Care Services. Washington, DC: U.S. Department of Health and Human Services: Office of Disability, Aging and Long-Term Care Policy, 2000.

<sup>46</sup> O'Brian, E., and R. Elias. Medicaid and long-term care. Washington, DC: Kaiser Commission on Medicaid and the Uninsured, (2004, May) <<http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=36296>> (10 Jan 2004)

<sup>47</sup> U.S. General Accounting Office. 2002. Aging Baby Boom Generation Will Increase Demand and Burden on Federal and State budgets [GAO-02-544T]. <<http://www.gao.gov/new.items/d02544t.pdf>> (10 Jan 2004)

<sup>48</sup> Burwell, B., K. Sredl, and S. Eiken. Medicaid long-term care expenditures in FY 2003[Addendum]. Cambridge: The Medstat Group, 2004.

<sup>49</sup> See note 45 above.

<sup>50</sup> National Association for Home Care. Basic Statistics about Home Care. Washington, DC: Author. Findings based on Centers for Medicare and Medicaid Services, MSIS, 2004.

<sup>51</sup> See note 30 above.

<sup>52</sup> Kassner, E. Medicaid and Long-Term Services and Supports for Older People: Fact Sheet. Washington, DC: AARP Public Policy Institute, 2005.

<sup>53</sup> Miller, N.A., C. Harrington, E. Goldstein. 2002. Access to community-based long-term care: Medicaid's role. Journal of Aging and Health Volume 14, No. 1: 138-59.

<sup>54</sup> Metlife Market Survey of Nursing Home and Home Care Costs, 2004.

<sup>55</sup> See note 30 above.

<sup>56</sup> Hoffman, C., D. Rice and H.Y. Sung. 1996. Persons with Chronic Conditions: Their Prevalence and Costs. JAMA 276 (18), 1473-1479.

<sup>57</sup> Niefeld, M., E. O'Brien, and J. Feder. Long-term care: Medicaid's role and challenges. Washington, DC: Kaiser Commission on Medicaid and the Uninsured, 1999.

<sup>58</sup> VanDerhei, J., and C. Copeland. Can America Afford Tomorrow's Retirees: Results from the EBRI-ERF retirement security projection model [Issue brief # 263]. Washington DC: Employee Benefit Research Institute, 2003.

<sup>59</sup> O'Brian, E., and R. Elias. Medicaid and long-term care. Washington, DC: Kaiser Commission on Medicaid and the Uninsured, 2004. <<http://www.kff.org/medicaid/loader.cfm?url=/commonspot/security/getfile.cfm&PageID=36296>> (10 Jan 2004)

## Resources

### **Southern Caregiver Resource Center**

3675 Ruffin Road, Suite 230  
San Diego, CA 92123  
(858) 268-4432; (800) 827-1008 (in CA)  
E-mail: [scrc@caregivercenter.org](mailto:scrc@caregivercenter.org)  
Web site: [www.caregivercenter.org](http://www.caregivercenter.org)

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

### **Family Caregiver Alliance**

235 Montgomery Street, Suite 950  
San Francisco, CA 94104  
(415) 434-3388; (800) 445-8106  
Web site: [caregiver.org](http://caregiver.org)  
E-mail: [info@caregiver.org](mailto:info@caregiver.org)

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.