

Chapter 9: Long-term Care

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Long-term care (LTC) generally brings to mind images of nursing homes and older people living in them who can no longer care for themselves. In truth, long-term care comes in many different forms and is provided in many different settings.

It is institutional care. It is assisted living. It is also home - and community-based services, including home health care, adult day care, home delivered meals and other services authorized under Title III of the Older Americans Act.¹ (See chart, "Numbers of People Receiving Home and Community-Based Services, 2006.")

These services are financed by Medicaid, Medicare, private long-term care insurance, private out-of-pocket spending and appropriations under the Older Americans Act. (Despite what many Americans believe, Medicare is not a major payer for LTC, as discussed later.)

Yet the majority of long-term care services aren't paid for at all. They are provided by 52 million unpaid caregivers - primarily family members and friends of those needing LTC. Their services, if paid for,

would have cost an estimated \$375 billion in 2007 - almost double what the federal government spent that year on Medicaid.^{2, 3}

LTC serves both people who are over the age of 65 and people under that age (for example, see box, "Nursing Home Residents by Age & Gender").

COST AND FINANCING OF LONG-TERM CARE

In 2008, the average annual cost of a private room in a nursing home was more than \$76,000.⁴ The average cost for an assisted living facility in 2007 was \$35,628.⁵ (See glossary for the differences between the two.) These costs vary widely from region to region and are highest in the Northeast.⁶ Costs also vary by certification status, size and type of ownership of the facility.

MEDICAID

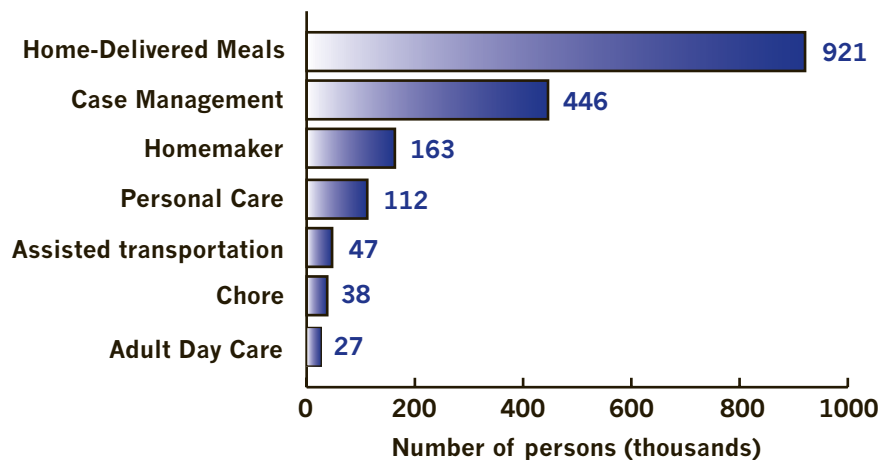
Medicaid is a public health insurance program funded by federal and state governments. (See chapter on Medicaid for more.) Medicaid is a major payer for long-term care because federal law requires that Medicaid programs in every state must provide nursing home care and home health care for the qualified poor.

FAST FACTS

- Two-thirds of people age 65 today will need some long-term care in their lifetimes.^a
- Of the 10 million Americans who need assistance with daily activities, 1.7 million live in the nation's 16,000 nursing homes and approximately 520,000 live in assisted living facilities.^b
- Fourteen percent of Americans age 85 or older live in nursing homes.^c
- A total of \$207 billion was spent on long-term care in the U.S. in 2005.^d
- Of total long-term care spending, Medicaid spending accounts for 49 percent, Medicare accounts for 20 percent, out-of-pocket spending equals 18 percent and private health and long-term care insurance makes up 7 percent.^e
- There are 52 million unpaid caregivers who contribute an estimated \$375 billion in value to the U.S. economy.^f

For story ideas on long-term care, see page 101. A list of experts and websites begins on page 102.

Numbers of People Receiving Home and Community-Based Services, 2006



Source: U.S. Administration on Aging (2006). "FY2006 U.S. Profile of OAA Programs." (www.aoa.gov/PROF/agingnet/NAPIS/SPR/2006/Profiles/us.pdf).

term stays in skilled nursing facilities - full coverage for 20 days, partial coverage for up to 80 additional days. This spending, plus spending for home health benefits for eligible Medicare beneficiaries, accounts for 20 percent of long-term care expenditures.¹⁰

PRIVATE LONG-TERM CARE INSURANCE

A relatively small number of people purchase long-term care insurance - approximately 7 million policies were in force in 2005.¹¹ Although it seems entirely logical to minimize the risk of impoverishment from the high cost of long-term care,

long-term care insurance has not had broad market appeal.

Younger people don't yet recognize the need for long-term care insurance, although the cost of it for them is low. When people are closer to the age when they might need long-term care, many cannot afford the then-high priced insurance premiums.

The Robert Wood Johnson Foundation, in 1987, initiated an experimental program called the Program to Promote Long-Term Care Insurance. Also referred to as the Partnership Program, it involves a public-private partnership between Medicaid and private insurance. Those buying long-term care insurance can protect a portion of their assets that otherwise would count against them were they to apply to Medicaid to cover their long-term care expenses. (See the Alliance for Health Reform issue brief on this topic at www.allhealth.org under "Resources.")

The Partnership Program began as a demonstration project in four states and is now available for replication in all states. Eighteen states had implemented Partnership Programs as of August 2008 and many others are in the process of implementing these programs.¹² All told, long-term care insurance pays for approximately 7 percent of national long-term care spending.¹³

9 Medicaid accounts for almost half of national long-term care spending.⁷ (See chart, "Financing of Long-Term Care, 2005.") Of that amount, most is for institutional care, though spending for non-institutional care is growing and reached 37 percent of Medicaid's share of LTC spending in 2005.⁸ Though over half of those who use Medicaid long-term care services are over 65, a third (34 percent) are disabled children and adults under 65.⁹

Beyond the basic federal requirements, Medicaid LTC benefits vary from state to state. Home and community-based services (HCBS) are provided under Medicaid waivers in all states but the programs serve limited populations, and vary greatly in scope from state to state. (See glossary for details about Medicaid waivers.) Since 2007, under a provision of the Deficit Reduction Act (DRA) of 2005, waivers are no longer required for some home and community-based services, such as case management, homemaker/home health aide services, personal care services, adult day health, and habilitation services.

MEDICARE

Though many people think that Medicare covers long-term care, in reality it provides only limited coverage of nursing home stays and home health care. Eligibility is based on, and follows, a hospital stay of at least three days. Medicare covers short-

OUT-OF-POCKET SPENDING

For people without insurance, including those who do not qualify for Medicare or Medicaid benefits, long-term care costs are paid out-of-pocket. This includes payment for nursing home care, assisted living and home health care. The average annual cost of home care by one industry estimate is close to \$44,000.¹⁴ Out-of-pocket spending accounts for 18 percent of national spending for long-term care.¹⁵

LIKELY POLICY DEBATES

FINANCING

As noted, Medicaid serves as the nation's safety net for individuals with long-term care needs. Many individuals who initially pay for nursing home care out of pocket become impoverished by the high cost of care and later qualify for Medicaid. Can Medicaid continue to fund the largest share of long-term care? Will state budgets hold up under the strain?

Policymakers also wonder how to support family caregiving and other informal caregivers. When family members stay home from work or leave their jobs to care for loved ones, this takes an economic toll on them and on society. How could governments reduce the strain?

Perhaps long-term care insurance can play a greater role. How can we increase its appeal and thereby its market share? Are consumer protections needed to allay fears that the insurance policies of today will cover the needs of tomorrow? What could be done to speed the replication of the Long-term Care Partnership Programs by states and encourage the uptake of its products by consumers?

Many states are experimenting with programs that reduce the need for nursing home placements.¹⁶ Such programs require that people needing long-term care be able to live in the most integrated setting appropriate. One innovative effort, Vermont's "global budgeting,"¹⁷ allows Medicaid funds to be spent on whichever service is most appropriate for

Nursing Home Residents by Age & Gender

AGE GROUP	TOTAL	MEN	WOMEN
64 OR YOUNGER	175,000	54%	46%
65 TO 84	643,000	34%	66%
85 OR OLDER	674,000	18%	82%

Source: AARP Public Policy Institute analysis of 2004 NNHS (http://www.aarp.org/research/longtermcare/nursinghomes/fs10r_homes.html).

persons found to be eligible for long-term care. Global budgets do not separate funding for nursing homes or home and community-based services into different "silos."

WORKFORCE

Throughout the health care arena there is a workforce shortage¹⁸ and this is dramatically so for direct care workers in long-term care.^{19,20} Studies have shown that quality of care is directly related to nurse staffing ratios,²¹ yet in very few states does the average staffing ratio meet the minimum standard recommended by each state.

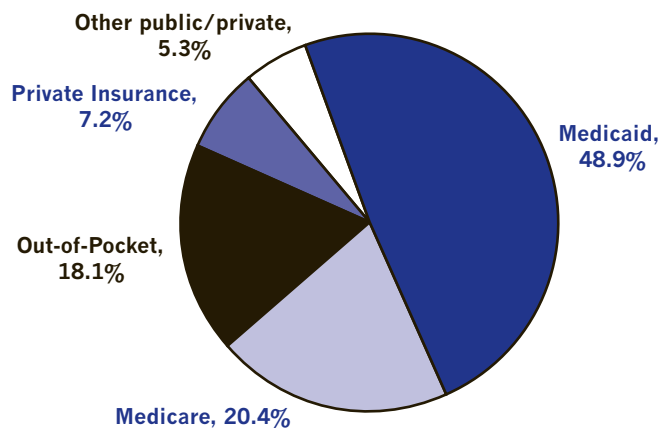
Certified nurse assistants (CNAs), who make up the majority of direct care providers in most facilities (see chart, "Distribution of Direct Care Workers"), get minimal training, benefits and opportunity for advancement. Questions abound on how to increase recruitment, retention and job satisfaction of direct care workers. The biggest question is: Will the workforce supply be ready to meet the baby boomer demand?

QUALITY OF CARE AND RESIDENT-DIRECTED CARE AND SERVICES

In 2007, nearly 17 percent of nursing homes inspected by state regulators were cited for serious deficiencies.²² Some say the inspection system is broken.²³ Others say quality of care is the issue, and that nursing home ownership is a contributing factor²⁴ (with most of the criticism lodged against certain for-profit chains). Lawmakers have proposed bills that, if passed, would improve transparency of ownership.²⁵

Medicaid reimbursement and other historical factors

Financing of Long-Term Care, 2005



Source: U.S. Dept. of Health and Human Services. "National Clearinghouse for Long-Term Care Information: Overview." (www.longtermcare.gov/LTC/Main_Site/Paying_LTC/Costs_Of_Care/Costs_Of_Care.aspx#Who)

have long fostered a bias toward institutional long-term care. To counteract this bias, researchers, policymakers, caregivers and providers are promoting new models of care and demonstrating them across the country.

Among these is the Green House® model, which provides person-centered long-term care in small home-like settings as an alternative to larger, institution-like nursing homes. (For more, see the Alliance issue brief "Changing the Nursing Home Culture" at http://www.allhealth.org/publications/Long-term_care/Changing_the_Nursing_Home_Culture_79.pdf.)

Studies have shown improved resident and caregiver satisfaction at these types of facilities.²⁶ But the question remains: Are current long-term care providers sufficiently motivated to make the necessary structural changes in older facilities that would be required to create a more individualized, home-like environment? Can they afford to do so?

In a 2008 survey of long-term care opinion leaders,²⁷ 84 percent felt that long-term care should be rebalanced away from traditional nursing homes and toward home and community-based services. Some 61 percent were in favor of expanding consumer-directed programs such as "Cash and Counseling," a way for those needing long-term care to direct expenditures made on their behalf. (Read more about Cash and Counseling at www.cashandcounseling.org/about.)

DISPARITIES

A 2007 study showed a relationship between racial segregation and quality disparities in U.S. nursing homes.²⁸ The study found that blacks were more likely to live in poor quality nursing homes than whites. Blacks were almost three times as likely to live in a nursing home housing predominantly Medicaid residents. The study offered policy recommendations including Medicaid payment reform that would close the gap between Medicaid per diem rates and those paid by private payers.

TIPS FOR REPORTERS

- It is a common misperception that Medicare covers long-term care. It is not well understood that the Medicare "long-term care" benefit is limited to 100 days of skilled care and that it must follow a hospital stay of three days or more. The Center for Medicare Advocacy has information about skilled nursing facility (SNF) care, therapy care, rehab care, and other Medicare issues on its web site, www.medicareadvocacy.org. You can also learn about Medicare benefits at www.cms.gov.
- There is often confusion between Medicare and Medicaid. It is not well understood that Medicaid covers long-term care for qualified individuals and that it is a means-tested benefit. Most publicly funded long-term care is financed by Medicaid.
- Gifts to family members or others within the five-year period prior to applying for Medicaid count as assets of the potential beneficiary for purposes of determining Medicaid eligibility. The period in which such gifts are counted as assets is known as the "look-back period." The "look-back period" for Medicaid changed from three years to five years in February 2006. It is commonly asserted that individuals divest themselves of assets in order to qualify for Medicaid and be eligible for long-term care coverage. However, studies have found little evidence of any truth behind this notion.²⁹
- The movement to resident-centered care or person-centered care is often linked with the Green House® movement. (NCB Capital Impact, with

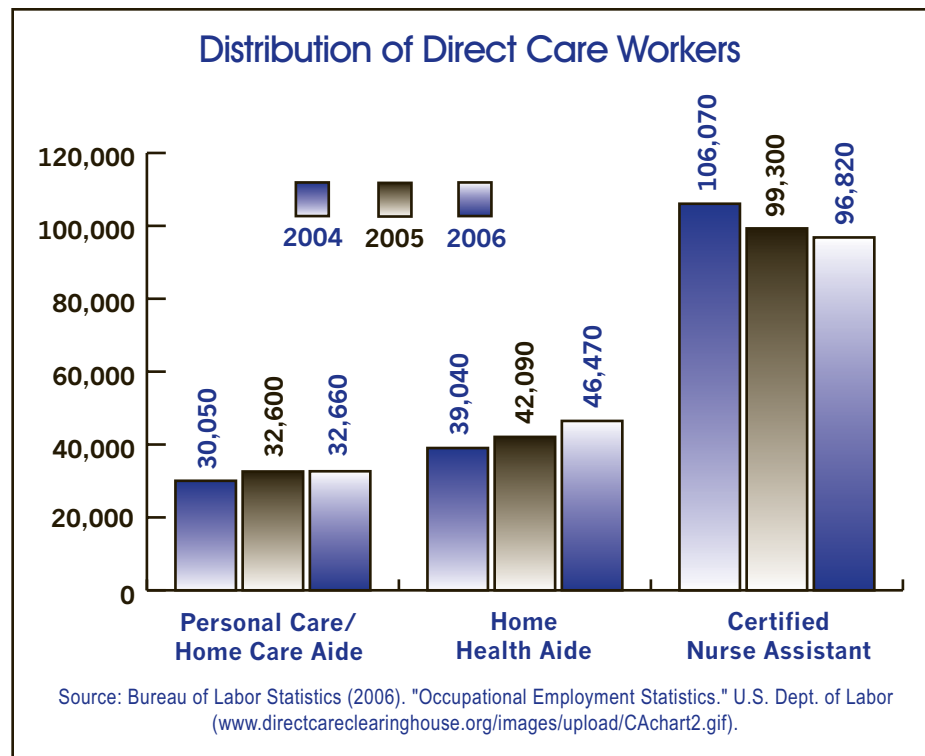
support from the Robert Wood Johnson Foundation, is pursuing the development of Green Houses across the country. For more information about this replication initiative, see <http://www.ncbcapitalimpact.org/default.aspx?id=146>.)

However, resident-centered care can and should occur in all long-term care facilities, not only ones of a particular architectural design. This movement has many shapes and forms depending on developments on the local and state level and subject to state and federal regulations. A good resource for information about this movement is www.pioneernetwork.net. The movement is also known as "culture change."

- Many long-term care facilities require residents to sign admissions agreements with mandatory arbitration clauses. There have been successful cases challenging the legality of such clauses. However, it is still a common occurrence. It is also common to request that a family member accept financial responsibility for their loved one in the facility. Family members are not required to accept such responsibility but often don't realize what they have signed until much later down the road.

STORY IDEAS

- Long-term care workforce and immigration - What are the effects of federal immigration reforms? Will tighter restrictions increase the workforce shortage?
- Long-term care costs and the economic downturn - How will state Medicaid budgets fare in the face of an economic downturn? What will happen to the long-term care safety net for the poor? Will families be able to continue their out-



of-pocket spending for long-term care? Will Medicaid enrollment swell?

- Facility residents' costs of care are paid for by a variety of sources such as out-of-pocket, private long-term care insurance and Medicaid. The mix of residents by payer source often varies by location of the facility. Will the economic downturn have an affect on the payer source mix of facilities in your community? Will private-pay facilities have to take in more Medicaid residents to fill their beds? Might we see more facility closures due to the economic recession?
- Are innovative models of care gaining market share? How is the Green House® project progressing? Has the economic downturn slowed progress to change institutional models of care into more home-like settings?
- Are baby boomers changing the face of long-term care? Are they requesting/demanding different services, benefits? Are more institutions offering email and Internet access to their residents? Will baby boomers find innovative solutions to aging at home? Will this speed the movement away from the current institutional bias? Are baby boomers more aware of "residents' rights?" For information about residents' rights

contact the National Long-term Care Ombudsman Resource Center. They have an information packed website at www.ltombudsman.org.

- Health reform - Is long-term care reform part of the discussion of health care reform? Can cost containment efforts be effective without encompassing the share spent by Medicaid and Medicare on long-term care?

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Websites

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www.aoa.gov

Alzheimer's Association
www.alz.org

American Association for Homes and Services for the Aging
www.aahsa.org

American Association of People with Disabilities
www.aapd-dc.org

American Institutes for Research
www.air.org

American Network of Community Options and Resources
www.ancor.org

America's Health Insurance Plans
www.ahip.org

Bazon Center for Mental Health Law
www.bazon.org

CBO, Health and Human Resources Division
www.cbo.gov/aboutcbo/organization/hhrd.htm

Center for Health Care Strategies
www.chcs.org

Center on an Aging Society, Georgetown University
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www.c-c-d.org

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www.thearc.org

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