

Chapter 5: Who Will Provide Care for Those Who Need It?

As the U.S. population ages, states' capacity to provide health and long-term care services will be tested. States must consider how to respond to an increasing demand for long-term care services not only in terms of providing enough care but also in terms of providing the type of care that consumers are likely to need and want. Achieving an optimal mix of good quality institutional and community-based care will likely be a challenge.

Currently, there is great variation across states in the types and amounts of long-term care services available to people with limited resources. States have considerable discretion with regard to decisions about who can receive care and what services will be provided through the Medicaid program. In addition, some state-funded long-term care services and programs are larger and more comprehensive than others.

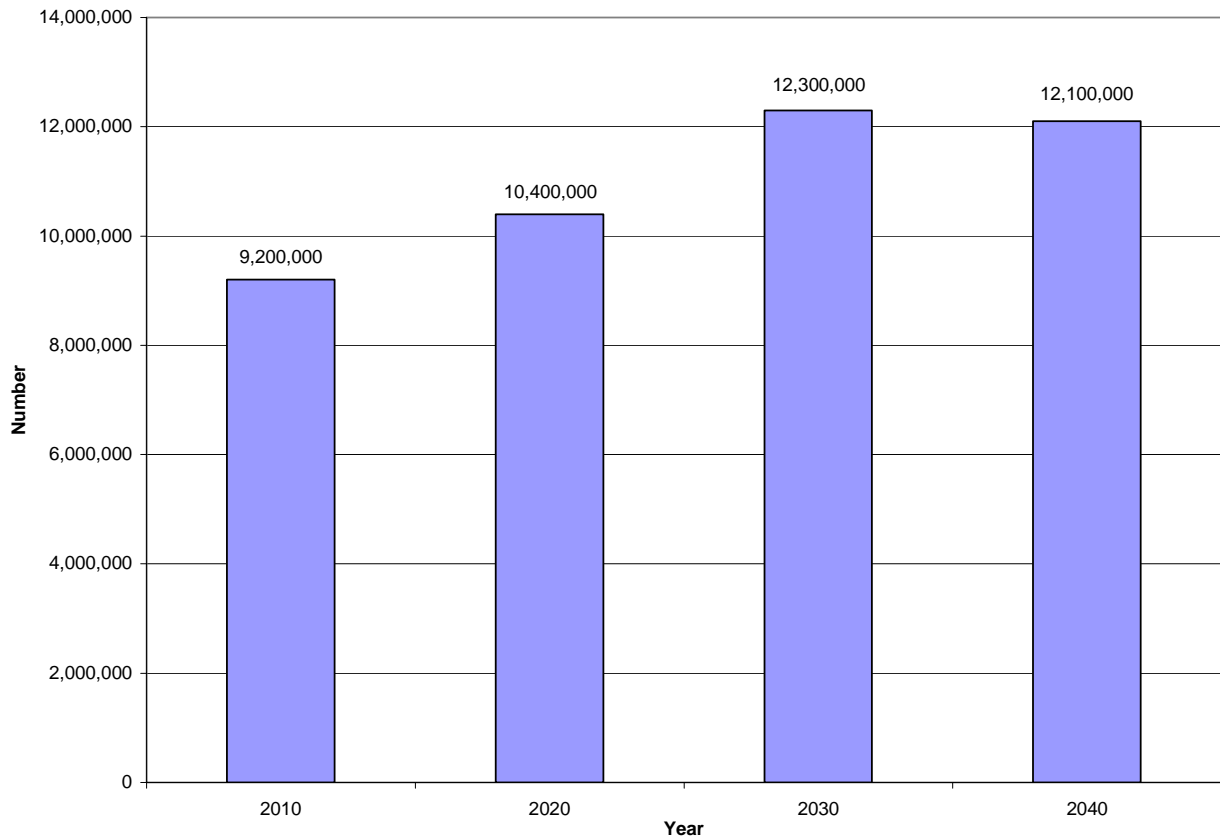
The shortage of paid caregivers in both institutional and community settings already has forced some states to think about how to successfully recruit and retain workers who can provide quality care, and this will continue to be an important issue. States can also take steps to support and encourage informal caregivers. In addition, states have a responsibility to monitor the quality of long-term care services. Some efforts to monitor the quality of care are in place now, but more attention to quality monitoring will likely be needed in the future.

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Millions of people are projected to need long-term care in the future

Projections of the Number of People Age 65 and Older Who Will Need Long-Term Care



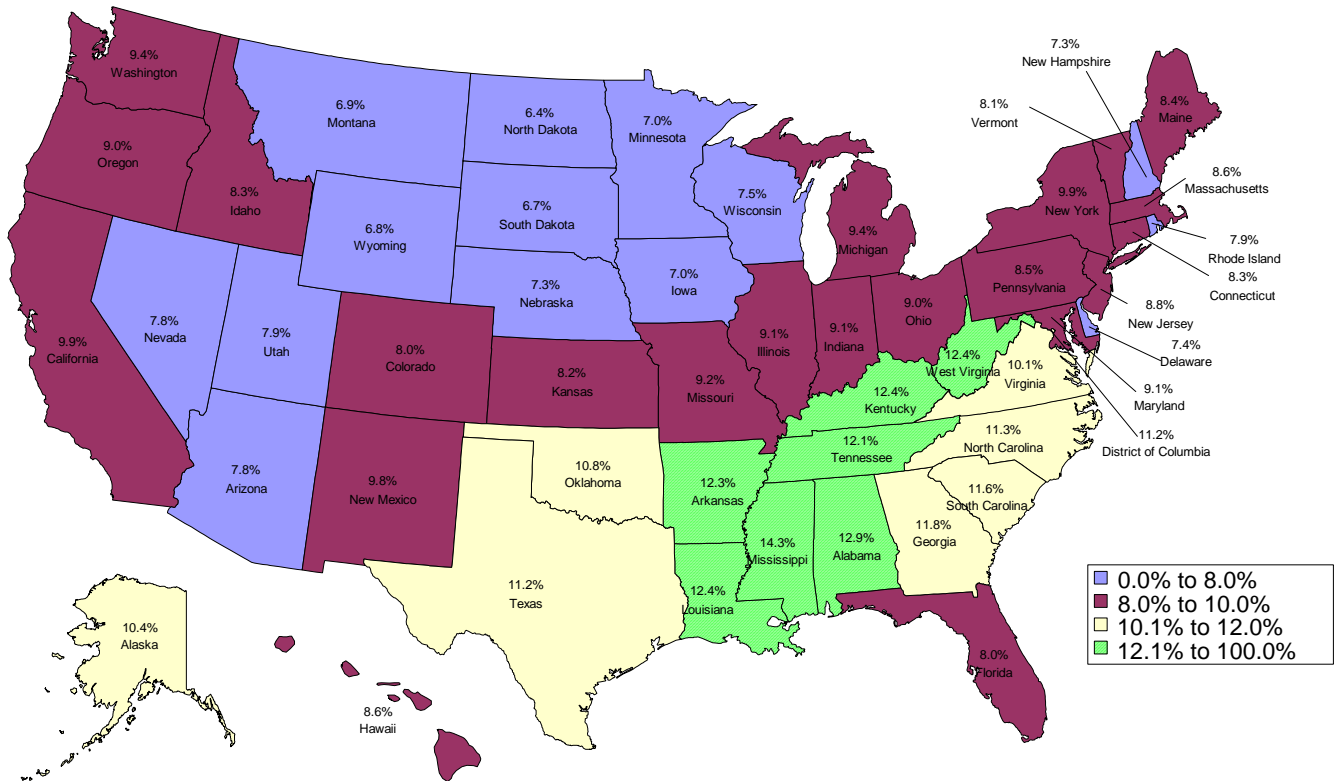
Source: Congressional Budget Office. (1999). *Projections of Expenditures for Long-Term Care Services for the Elderly*. Washington DC: Congressional Budget Office.

Note: CBO's calculations are based on data from the Lewin Group and the Center for Demographic Studies at Duke University.

Estimates based primarily on current disability rates and applied to the number of older Americans anticipated in the future suggest that more Americans will need long-term care in the future. People in need of long-term care will need a range of different services, depending on the type and severity of their disabilities.

Current disability rates provide some indication of future demand for long-term care services

Proportions of People Age 65+ with Activity Limitations, 2000



Source: U.S. Census Bureau. *Census 2000 Summary File 3 (Table P41)* [Data file]. Retrieved from the American FactFinder Web site, <http://factfinder.census.gov>.

Nationally, 9.5 percent of adults age 65 and older have physical, mental, or emotional conditions lasting six months or more that make it difficult to perform basic activities of daily life, such as dressing, bathing, or getting around inside the home. People of all ages have disabilities, but disabilities are more common among older people. Thus, growth in the number of older people, which is expected in every state, is likely to mean an increase in the number of people with disabilities, even if disability rates do not change.

Growth in the proportion of the oldest-old— who are most likely to need long-term care—differs across states

Percentage Change in the Population Age 85 and Older, 2000 to 2025

<i>Rank</i>	<i>State</i>	<i>% change</i>	<i>Rank</i>	<i>State</i>	<i>% change</i>	<i>Rank</i>	<i>State</i>	<i>% change</i>
1	Alaska	204%	18	New Mexico	88%	35	Michigan	47%
2	Utah	179%	19	North Dakota	79%	36	Kentucky	46%
3	Colorado	159%	20	Louisiana	77%	37	West Virginia	46%
4	Hawaii	155%	21	Georgia	76%	38	Connecticut	45%
5	Wyoming	152%	22	California	74%	39	Iowa	45%
6	Nevada	144%	23	Delaware	72%	40	New Jersey	42%
7	Idaho	136%	24	Tennessee	71%	41	Massachusetts	42%
8	Montana	123%	25	Maryland	67%	42	Kansas	40%
9	Oregon	121%	26	New Hampshire	66%	43	Mississippi	40%
10	Washington	114%	27	Minnesota	64%	44	Vermont	40%
11	North Carolina	102%	28	Ohio	59%	45	Illinois	40%
12	Arizona	102%	29	South Dakota	59%	46	Missouri	39%
13	South Carolina	98%	30	Nebraska	58%	47	Rhode Island	35%
14	Texas	97%	31	Alabama	55%	48	Pennsylvania	31%
15	Virginia	92%	32	Indiana	55%	49	New York	26%
16	Oklahoma	90%	33	Wisconsin	54%	50	District of Columbia	24%
17	Florida	89%	34	Arkansas	53%	51	Maine	21%

Source: (2000 data) U.S. Census Bureau. *Census 2000 Summary File 1 (Table PCT12)* [Data file]. Retrieved from the American FactFinder Web site, <http://factfinder.census.gov/>.

(2025 data) U.S. Census Bureau. *Detailed State Projections by Single Year of Age, Sex, Race, and Hispanic Origin: 1995 to 2025* [Data file]. Retrieved from <http://www.census.gov/population/www/projections/stproj.html>.

The extent to which states will have to prepare for an increase in the number of people needing long-term care services will depend on a number of factors, including the projected number of the oldest-old residents—people age 85 and older—and therefore most likely to need long-term care services. Nationally, a 66 percent increase is expected in the population age 85 and older between 2000 and 2025. The increase in the need for long-term care services may not be as great in states where a relatively large portion of the population already is 85 or older.

Workforce shortages among paraprofessionals are expected

Number of Additional Aides Needed in 2025 to Maintain 2000 State Ratios

<i>State</i>	<i>Number of Aides</i>
District of Columbia	212
South Dakota	515
Vermont	554
Mississippi	835
Wyoming	851
Rhode Island	887
Delaware	900
Maine	907
Nebraska	921
New Hampshire	962
North Dakota	1,227
Kansas	1,536
Alaska	1,733
Nevada	1,810
West Virginia	1,968
Arkansas	2,156
Kentucky	2,319
Iowa	2,762
Montana	2,794
Alabama	2,969
Hawaii	3,270
New Mexico	3,350
Maryland	3,579
Missouri	3,620
Connecticut	3,755
Utah	3,927
Idaho	3,997
Louisiana	4,063
Indiana	4,074
Tennessee	4,274
Georgia	4,373
Oklahoma	5,425
South Carolina	5,548
Illinois	5,823
Massachusetts	5,869
Pennsylvania	6,084
Wisconsin	6,264
New Jersey	7,798
Oregon	7,823
Virginia	8,780
Arizona	10,362
Michigan	10,506
Colorado	10,813
Washington	12,476
Minnesota	12,734
Ohio	15,363
Florida	22,371
North Carolina	22,709
California	25,402
New York	27,950
Texas	55,280

Source: Center on an Aging Society analysis of data from (Home Health Aid data) Bureau of Labor Statistics. *2001 National Occupational Employment and Wage Estimates - Healthcare Support Occupations* [Data file]. Retrieved from www.bls.gov/oes/2001/oesrcst.htm.

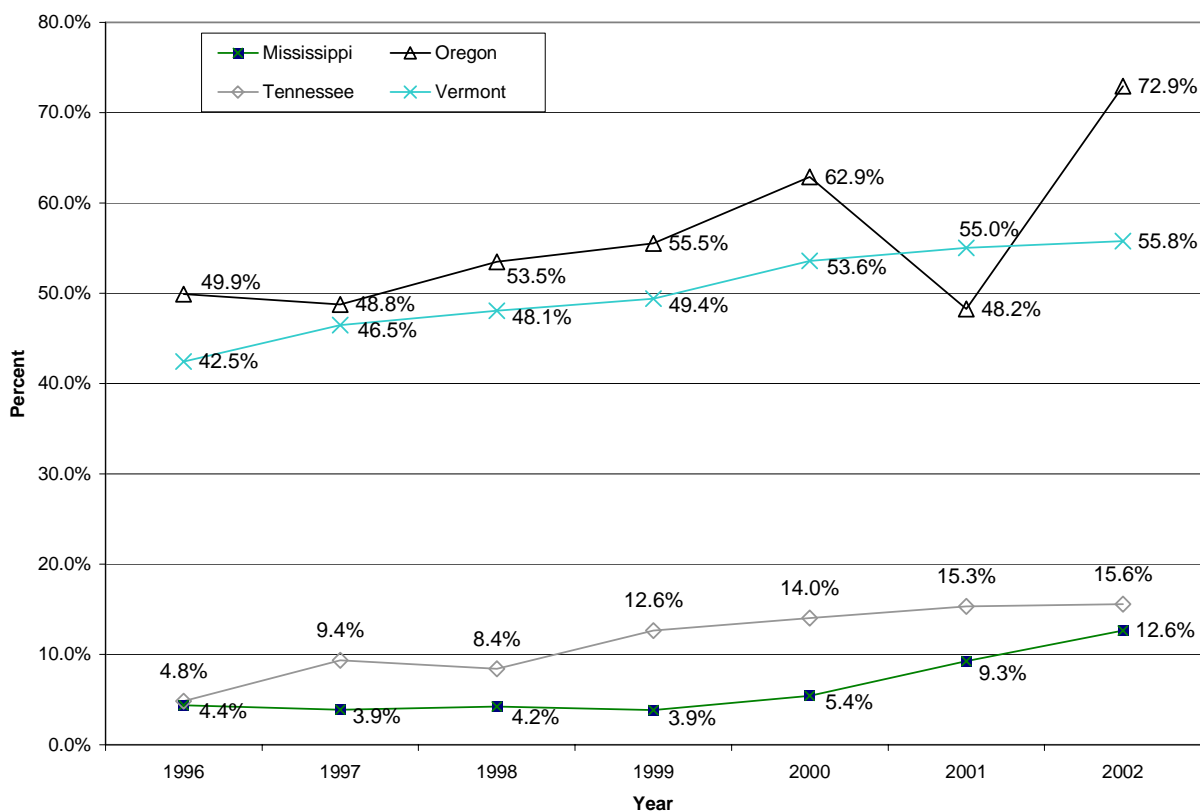
(2000 population data) U.S. Census Bureau. *Census 2000 Summary File 1* (Table PCT12) [Data file]. Retrieved from the American FactFinder Web site, <http://factfinder.census.gov>.

Projections from the Federal Bureau of Labor Statistics indicate substantial growth in employment for health care providers. In the case of long-term care workers, the demand may continue to exceed the supply of available workers. The U.S. Department of Health and Human Services projects, for example, that there will be substantial shortages of paraprofessionals, such as home health aides and nursing aides.

Current shortages and high turnover rates for paraprofessionals are due in part to the fact that paraprofessionals are asked to perform low-wage work that is physically and emotionally demanding. Recruitment and retention of these workers is particularly difficult in a strong economy. To maintain the ratio of providers of long-term care services to people age 85 and older, the pool of providers would have to increase by the same proportion as the expected number of people in this age group. The use of current ratios for home health aides may not be the best predictor of future needs, however, because states are already responding to the increased demand for community-based long-term care services and several changes in the delivery of long-term care services are expected.

A shift to more community-based care is anticipated

**Percent of Medicaid Long-Term Care Spending
Devoted to Home and Community-Based Care in Four States, 1996-2002**



Source: Home and Community Based Services (HCBS). (2003). *Medicaid Long-Term Care Expenditures, FY2002 and FY2001* [Data file]. Retrieved from http://www.hcbs.org/hcbs_data.htm.

Note: Mississippi and Tennessee had the smallest proportions and Oregon and Vermont had the largest proportions of Medicaid long-term care spending for home and community-based services in 1996.

In the last decade, the demand for alternatives to nursing home care has increased and the supply of other types of facilities and arrangements has grown.

- In the Medicaid program, which accounted for 44 percent of spending for long-term care in the United States in 2001, the majority of spending is for care in institutions such as nursing homes, but the proportion of spending for home and community-based care more than doubled over the last decade.
- Currently, the proportion of Medicaid spending for community-based long-term care in states ranges from 10 percent in Louisiana to 73 percent in Oregon.

- The shift from institutional to community-based care in Medicaid is occurring more rapidly in some states than in others but the trend is expected to continue in all states.

Home and community-based care can be provided in a variety of settings, including people's own homes as well as in assisted living facilities, which furnish care in a congregate residential setting, have become much more common in the last few years.

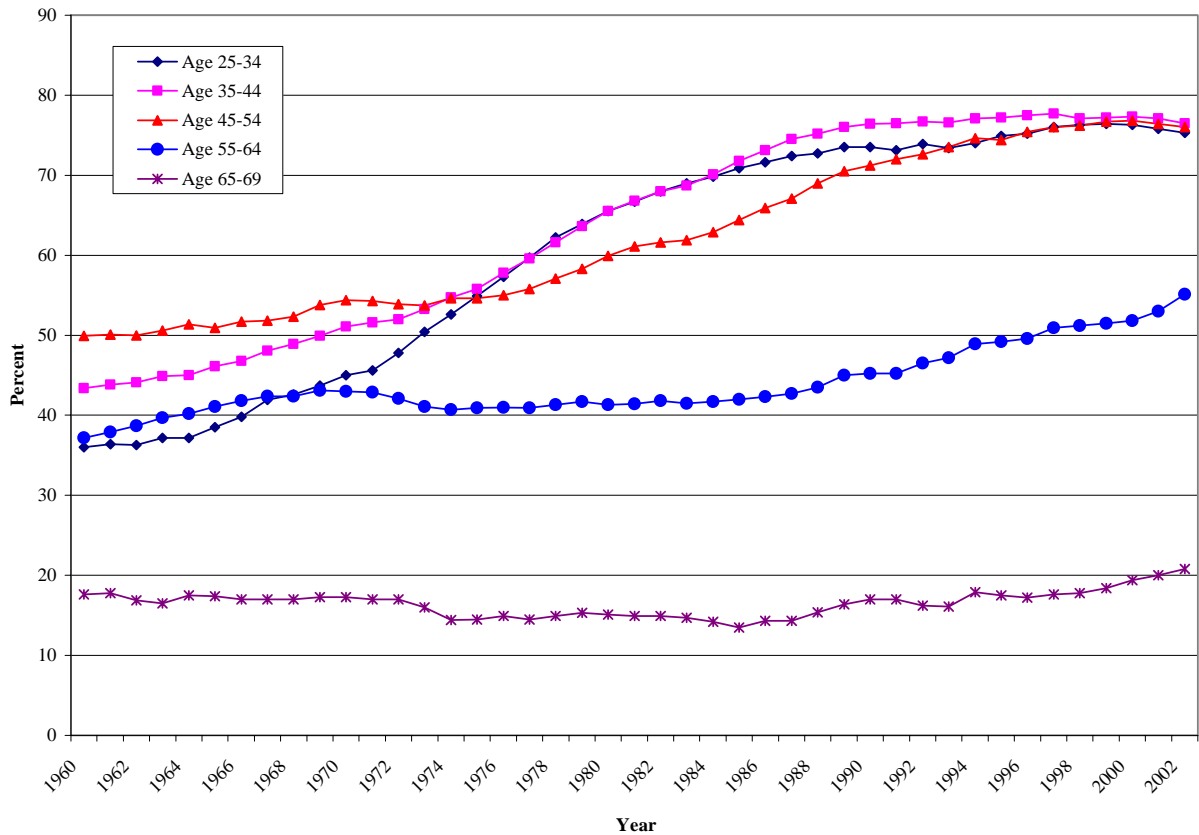
- The number of assisted living beds has grown from about 600,000 in 1998 to 910,000 in 2002 and is projected to be at 1.9 million by 2030.¹
- The use of hospice service—another alternative to institutional care—has also increased. Some 23 percent of Medicare beneficiaries who died in 2000 used hospice services compared to only nine percent of those who died in 1992.²

¹ (1998 and 2002 data) Mollica, R. (November 2002). *State Assisted Living Policy, 2002*. Portland, ME: National Academy for State Health Policy. (2030 data) Kraditor, K. (2001). *FACTS and TRENDS: The Assisted Living Sourcebook 2001*. Washington, DC: National Center for Assisted Living.

² Moon, M. & Buccuti, C. (2002). *Medicare and End-of-Life Care*. Washington DC: The Urban Institute.

Traditional caregivers may not be available

Labor Force Participation Rates for Women, by Age



Source: Bureau of Labor Statistics. *Labor Force Statistics from the Current Population Survey (Labor Force Participation Rate - Civilian Population, '25 - 34', '35 - 44', '45 - 54', '55 - 64', '65 - 69' yrs. Female)* [Data file] Retrieved from <http://data.bls.gov/cgi/bin/srgate>.

Women of all ages are more likely to be in the labor force today than they were 40 years ago. As a consequence, fewer women are available to take on the traditional role of caregiver for family members. Families will continue to play an important role in ensuring that people who need care receive it, but in the future, more assistance will probably be required.

While some older people receive care, others are caregivers

Number of Grandparents Responsible for Meeting the Basic Needs of Grandchildren, by State

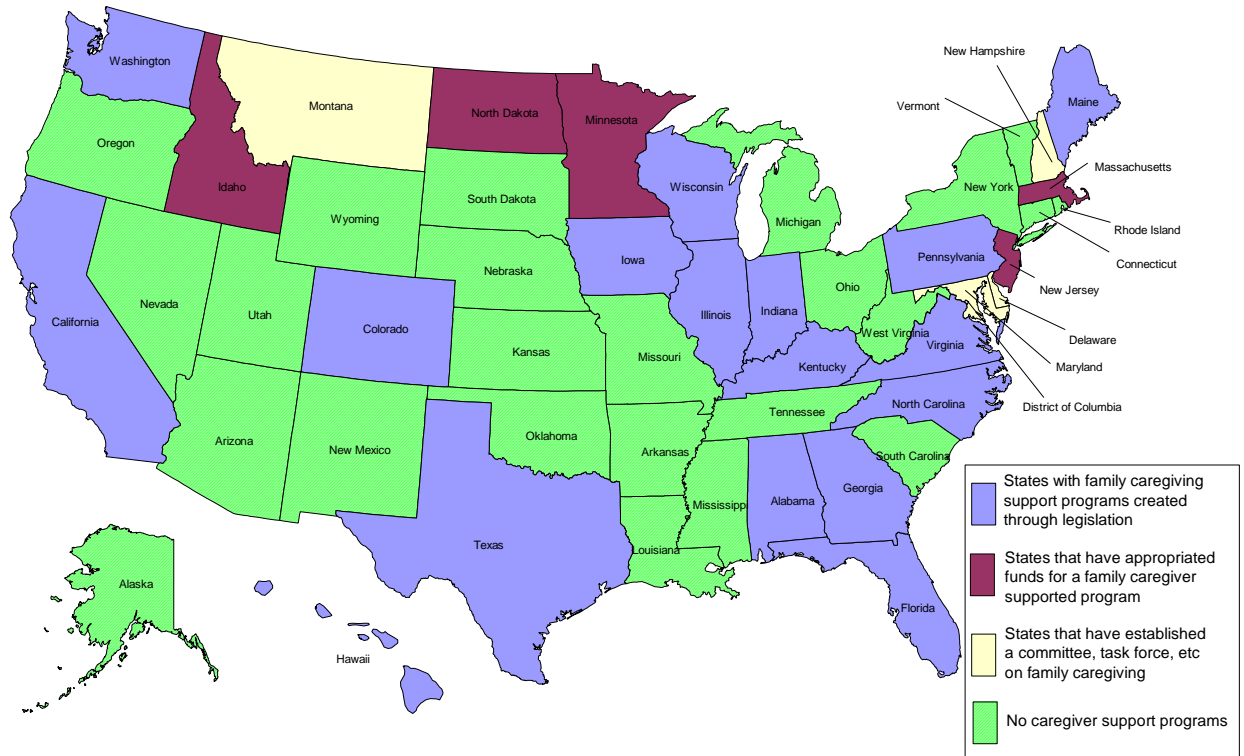
<i>State</i>	<i>Number of Grandparents</i>	<i>State</i>	<i>Number of Grandparents</i>
Alabama	56,369	Montana	6,053
Alaska	5,419	Nebraska	8,454
Arizona	52,210	Nevada	18,685
Arkansas	33,618	New Hampshire	4,534
California	294,969	New Jersey	58,789
Colorado	28,524	New Mexico	24,041
Connecticut	18,898	New York	143,014
Delaware	7,204	North Carolina	79,810
District of Columbia	8,183	North Dakota	2,547
Florida	147,893	Ohio	86,009
Georgia	92,265	Oklahoma	39,279
Hawaii	14,029	Oregon	22,103
Idaho	8,110	Pennsylvania	80,423
Illinois	103,717	Rhode Island	5,060
Indiana	48,181	South Carolina	51,755
Iowa	13,073	South Dakota	4,632
Kansas	17,873	Tennessee	61,252
Kentucky	35,818	Texas	257,074
Louisiana	67,058	Utah	15,989
Maine	5,074	Vermont	1,934
Maryland	50,974	Virginia	59,464
Massachusetts	27,915	Washington	35,341
Michigan	70,044	West Virginia	16,151
Minnesota	17,682	Wisconsin	23,687
Mississippi	48,061	Wyoming	3,582
Missouri	43,907	U.S. Total	2,426,730

Source: Casey Family Programs. (2002). *Nationwide Statistical Summary: Grandparents and Other Relatives Raising Grandchildren*. Washington DC: National Center for Resource Family Support.

The pool of potential caregivers may become more varied in the future. Longer life expectancies make it more likely that there will be grandchildren who can assist family members. With more divorce, there may be more ex-spouses involved with the care of former family members. And more older people may provide care for other family members.

States provide some support for family caregivers

State Family Caregiver Laws, 2003



Source: Tanner, R. (July 2003). *Family Caregiving* (Issue Brief). Washington, DC: Health Policy Tracking Service [Data file] Retrieved from <http://www.hpts.org>.

Note: Information for the District of Columbia was not available.

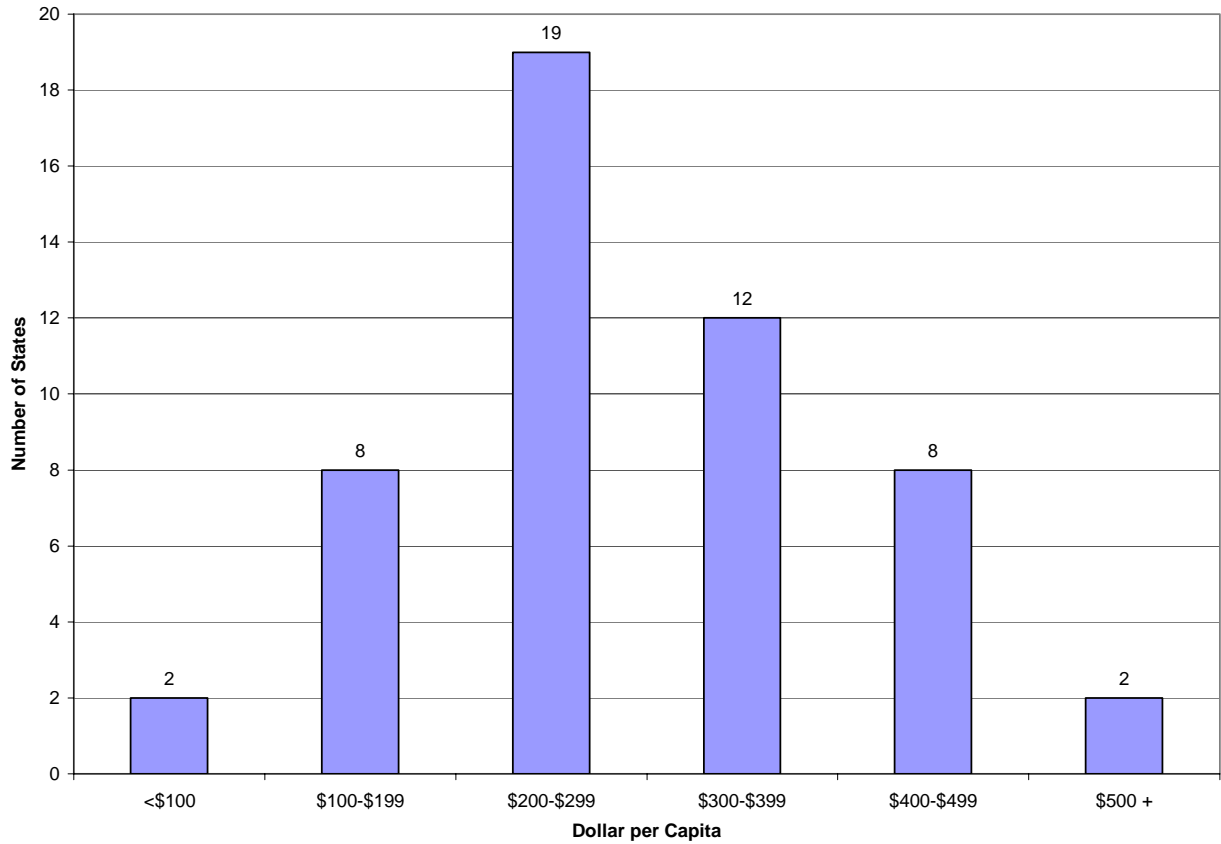
Given the preference of most families to care for their own—and the financial necessity for most families to do so—families will almost certainly continue to play a major role in providing care.

- Employers have already responded to changing family needs, both in the area of child care and by recognizing “eldercare” and specific eldercare rights were established in the Family and Medical Leave Act of 1992.
- The National Family Caregiver Support Program of 2001, is a Federally-funded program that provides grants to states to make information and

support services for family caregivers available. In addition, some states have enacted legislation related to family caregiving.

Spending for long-term care varies by state

FY2002 Medicaid Long-Term Care Expenditures Per Capita, 2002



Source: Home and Community Based Services (HCBS). (2003). *Medicaid Long-Term Care Expenditures, FY2002* [Data file]. Retrieved from http://www.hcbs.org/hcbs_data.htm.

Note: Expenditures per capita is the total Medicaid expenditures divided by the total state population.

Per capita spending is another measure that indicates the extent to which long-term care services differ in states.