



# Making the Case: Saving Your State's Caregiver Support Programs

## Talking Points for Advocates, Administrators, Providers and Caregivers

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States are currently struggling with one of the deepest recessions on record. As a result, funding for essential services has been reduced or, in the worst cases, eliminated; the most vulnerable people in society have been forced to survive on even less; and social service providers have had to fight for the survival of their programs and agencies.

Services for family caregivers are no exception. Across the country, budgets for publicly funded caregiver support programs are among those not only reduced, but threatened with further cuts or elimination as state revenues continue to drop. These cuts could undo years of hard work establishing programs that focus on the health and well-being of family caregivers and their capacity to provide quality long-term care to their loved ones.

**This paper is intended to help advocates, program administrators, service providers and caregivers fight for their state and local caregiver support programs. It includes background information, statistics, talking points and a list of additional resources to help make the case for maintaining public funding for crucial caregiver support services.**

### STATES IN CRISIS

Going into Fiscal Year (FY) 2010, 48 states faced budget shortfalls totaling at least \$166 billion. Consequently, at least 39 states cut key services that provide support to vulnerable residents. Of those, 23 states made cuts in services to older and/or disabled adults, including medical, rehabilitative, home care, day care and other needed services, and 21 states made cuts to health care programs.<sup>1</sup>

Unfortunately, the situation going forward looks just as bleak. Not quite half-way into FY 2010, state revenues have already fallen short of projections and mid-year shortfalls have opened up in 26 states. In addition, projections indicate that states will face shortfalls in the upcoming FY 2011 as big as or bigger than they faced this year.<sup>2</sup> This will most certainly lead to continued spending cuts and fewer services for poor and vulnerable populations.

Caregiver support programs in every state are vulnerable to attack. Many have already suffered significant public funding cuts. There is also the threat that what happened in California will happen elsewhere: lawmakers will threaten to revoke enabling legislation that originally established state-funded caregiver support programs in order to eliminate any future liability for the programs.

Each state receives National Family Caregiver Support Program (NFCSP) federal dollars appropriated under Title III E of the Older Americans Act. The NFCSP provides family caregivers with the following services:

- 1) Information about caregiver support services
- 2) Assistance in accessing supportive services
- 3) Individual counseling, support groups and caregiver training to help with decision-making and problem-solving
- 4) Respite care
- 5) Supplemental services, such as home modifications, emergency response systems, legal consultation and transportation

Requiring a 25% match from state and/or local sources, the NFCSP is administered by State Units on Aging and local Area Agencies on Aging. In many cases, these agencies contract with local nonprofit organizations to deliver services directly to caregivers. Consequently, both public and nonprofit agencies have absorbed the impact of budget cuts, laying off and furloughing employees and cutting services to caregivers.

In addition to the NFCSP, some states have specific state-funded caregiver support programs. These programs, as well as the matching funds for the NFCSP, all are potential targets for funding cuts.

Without action from advocates, service providers and program administrators in state capitals—and without caregivers raising their voices in protest—lawmakers will see caregiver support programs as easy targets and they will cut funding so desperately needed to serve caregiving families.

## **THE IMPACT OF CAREGIVING**

Estimated to be over 44.4 million, family caregivers are the largest source of long-term care services in the United States. In 2009, more than three in ten U.S. households (31%) reported that at least one person served as an unpaid family caregiver in the previous 12 months.<sup>3</sup> In addition to the important role they play in the lives of those with chronic conditions and disabilities, caregivers impact states by saving them

millions of dollars. At the same time, providing care can have adverse consequences on caregivers' health and well-being.

- The economic value of the care provided by family caregivers across the U.S. totals \$375 billion nationwide.<sup>4</sup> See the attached chart with data on the number of caregivers and economic value of caregiving in each state.
- Adults with long-term care needs typically want to remain at home or in the community,<sup>5</sup> rather than move into a skilled nursing facility, and they prefer to receive care from a family member or friend. In response to this need, at some point during the year, 52 million adults will provide care (estimate for 2005).<sup>6</sup>
- Family caregivers are the main provider of long-term care services in all states.<sup>7</sup> Nationwide, more than three-quarters (78%) of adults age 18 and older who receive long-term care at home rely exclusively on family caregivers.<sup>8</sup>
- The population is aging, and with it, our reliance on family caregivers. From 2007 to 2030, the population age 65 and older is expected to grow by 89%; the population age 85 and older is expected to increase by 74% over that same period. Concurrently, the number of people with long-term care needs is rising. While about 13 million adults in the U.S. (over half of whom were 65 years or older) needed long-term care services in 2000, by 2050 that number is expected to rise to 27 million, an increase of over 100%.<sup>9</sup> As a consequence, the burden on family and friends to provide care will only increase.
- Family caregivers suffer from higher levels of stress and depression compared to noncaregivers.<sup>10</sup> A 2009 survey found that three in ten caregivers (31%) consider their caregiving situation to be emotionally stressful.<sup>11</sup>
- Caregivers have lower levels of subjective well-being and physical health than noncaregivers. In 2005, caregivers reported chronic conditions (including heart attack/ heart disease, cancer, diabetes and arthritis) at nearly twice the rate of noncaregivers (45% versus 24%).<sup>12</sup> In a 2009 survey, 17% of caregivers reported feeling that their health had gotten worse as a result of caregiving.<sup>13</sup>

## MAKING THE CASE

- **States must invest in family caregivers' well-being so they can remain in their caregiving role.** Given the millions of dollars caregivers save states by providing uncompensated care and by helping to delay or prevent costly residential care, it is incumbent on states to spend a fraction of that savings to provide caregivers with needed support and services so they don't burn out.
  - In a 2005 survey of caregivers who received NFCSP services, over half of those surveyed (54%) said that caregiver support services enabled the care recipient to live at home for a longer period of time.<sup>14</sup>
  - According to a study published by the Office of Disability, Aging and Long-Term Care Policy in the U.S. Department of Health and Human Services, if an "intervention could eliminate high stress, the rate of admission [to a skilled nursing facility] among elders with highly

stressed caregivers could be reduced from about 27% to about 10% over a two-year follow-up.”<sup>15</sup>

- **When caring for friends and family members at home, family caregivers are saving states money on costly residential services.** In the absence of family caregivers, states are often forced to spend more on long-term care for older adults and adults with disabilities.
  - States spent an average of \$26,096 per Medicaid beneficiary living in a nursing facility in 2005.
  - States spent an average on \$9,459 per Medicaid beneficiary receiving home and community-based services in 2005.
- **Caregivers are suffering in this economy—now is not the time to take away their support services.** A 2009 caregiver survey<sup>16</sup> revealed:
  - More than two in five (43%) working caregivers have had their work hours or pay cut; 15% report that the downturn has caused them to lose their job or be laid off; and 30% say the downturn has caused them to work more hours or get an additional job.
  - Half of respondents reported that the economic downturn has increased their stress about being able to continue providing care.
- **The more financial and emotional stress caregivers experience as a result of the recession—coupled with a reduction in caregiver support services—the more likely they and their care recipients are to need other public safety net programs.** The impact of this will be almost immediate, as demand for services increases while the means to provide those services decreases.
  - According to a study published by the Office of Disability, Aging and Long-Term Care Policy in the U.S. Department of Health and Human Services, “caregiver stress is an important and highly significant predictor of nursing home entry.”<sup>17</sup>
  - Care recipients are now worse off, receiving less financial help from their caregivers. A 2009 survey of caregivers found that, in this recession, a smaller share of low-income caregivers (those with household incomes less than \$25,000) now help pay for their care recipient’s basic necessities (57% prior to the downturn vs. 44% now).<sup>18</sup>
- **Caregiver support programs provide family caregivers with services that can help reduce their stress, improve their well-being and assist them in their caregiving role.**
  - A 2005 survey of caregivers who received NFCSP services revealed that “caregiver support services affected the lives of caregivers and care recipients in meaningful and diverse ways.” More than three out of four (77%) caregivers reported that the support services they received helped them to better understand how to obtain resources and how to feel less stress associated with their role.<sup>19</sup>
  - Caregivers want support. A 2009 survey revealed that three-quarters (78%) of caregivers surveyed wanted more help or information about various caregiving topics.<sup>20</sup>

## THE TIME TO ACT IS NOW!

As governors and states prepare for the next budget cycle, they need to hear from all those impacted by family caregiving—those who provide services to caregivers, those who run long-term care and caregiver support programs, those who receive care from a family member or friend, and especially from caregivers themselves. Take the arguments presented here and tell your own personal stories and experiences to your lawmakers. They need to hear how important caregiver support programs are and how many people will be impacted if those services go away.

## ADDITIONAL RESOURCES

### *State Fiscal Crisis:*

Johnson, N., Oliff, P., & Williams, E. (2009, October 20). *An update on state budget cuts*. Washington, DC: Center on Budget and Policy Priorities. Available at <http://www.cbpp.org>

Lav, I.J., Johnson, N., & McNichol, E. (2009, November 11). *Additional federal fiscal relief needed to help states address recession's impact*. Washington, DC: Center on Budget and Policy Priorities. Available at <http://www.cbpp.org>

McNichol, E. & Johnson, N. (2009, October 20). *Recession continues to batter state budgets; State responses could slow recovery*. Washington, DC: Center on Budget and Policy Priorities. Available at <http://www.cbpp.org>

Pew Center on the States. (2009, November). *Beyond California: States in fiscal peril*. Washington, DC: Author. Available at <http://www.pewtrusts.org/>

### *State Caregiving and Long-Term Care Statistics:*

Houser, A. & Gibson, M.J. (2008, November). *Valuing the invaluable: The economic value of family caregiving, 2008 Update*. Washington, DC: AARP Public Policy Institute. Available at <http://www.aarp.org/research/ppi/>

State Profiles—Include background information and statistics on socio-demographics, long-term care and caregiving in each state. Published by Family Caregiver Alliance. Available at [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1789](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1789)

## Endnotes

- 1 Center on Budget and Policy Priorities. (2009, June 29). New fiscal year brings painful spending cuts, continued budget gaps in almost every state. [Press Release]. Washington, DC: Author. Accessed on November 16, 2009 <http://www.cbpp.org/cms/index.cfm?fa=view&id=2853>
- 2 McNichol, E. & Johnson, N. (2009, October 20). *Recession continues to batter state budgets; State responses could slow recovery*. Washington, DC: Center on Budget and Policy Priorities.. Accessed on November 16, 2009 <http://www.cbpp.org/cms/index.cfm?fa=view&id=711>
- 3 National Alliance for Caregiving and AARP. (2009, November). *Caregiving in the U.S. 2009*. Washington, DC: Author.
- 4 Houser, A. & Gibson, M.J. (2008, November). *Valuing the invaluable: The economic value of family caregiving, 2008 Update*. Washington, DC: AARP Public Policy Institute. Accessed November 18, 2009 [http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13\\_caregiving.html](http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13_caregiving.html)
- 5 Houser, A., Fox-Grage, W., & Gibson, M.J. (2006). *Across the states: Profiles of long-term care and independent living* (7th ed.). Washington, DC: AARP Public Policy Institute.
- 6 Houser, A. & Gibson, M.J. (2008, November). *Valuing the invaluable: The economic value of family caregiving, 2008 Update*. Washington, DC: AARP Public Policy Institute. Accessed November 18, 2009 [http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13\\_caregiving.html](http://www.aarp.org/research/ppi/health-care/health-costs/articles/i13_caregiving.html)
- 7 Houser, A., Fox-Grage, W., & Gibson, M.J. (2009). *Across the states: Profiles of long-term care and independent living* (8th ed.). Washington, DC: AARP Public Policy Institute.
- 8 Thompson, L. (2004, March) *Long-term care: Support for family caregivers*. [Issue Brief]. Washington, DC: Georgetown University, Long-Term Care Financing Project.
- 9 U.S. Department of Health and Human Services & U.S. Department of Labor. (2003, May 14). *Future supply of long-term care workers in relation to the aging baby boom generation* (Report to Congress). Washington, DC: Author.
- 10 Family Caregiver Alliance. (2006). *Caregiver health*. [Fact Sheet] San Francisco: Author. Available at Family Caregiver Alliance website, <http://www.caregiver.org>
- 11 National Alliance for Caregiving and AARP. (2009, November). *Caregiving in the U.S. 2009*. Washington, DC: Author.
- 12 Family Caregiver Alliance. (2006). *Caregiver health*. [Fact Sheet] San Francisco: Author. Available at Family Caregiver Alliance website, <http://www.caregiver.org>
- 13 National Alliance for Caregiving and AARP. (2009, November). *Caregiving in the U.S. 2009*. Washington, DC: Author.
- 14 Beauchamp, J. & Trebino, L. (2007, March). *Results from the Administration on Aging's third national survey of Older Americans Act program participants* [Final Report submitted to U.S. Department of Health and Human Services]. Washington, DC: Mathematica Policy Research, Inc
- 15 Spillman, B.C. & Long, S.K. (2007, January). *Does high caregiver stress lead to nursing home entry?* Washington, DC: U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care. Accessed November 18, 2009 <http://aspe.hhs.gov/daltcp/reports/2007/NHentry.pdf>
- 16 Evercare & National Alliance for Caregiving. (2009, April 28). *The economic downturn and its impact on family caregiving*. Washington, DC: Author.
- 17 Spillman, B.C. & Long, S.K. (2007, January). *Does high caregiver stress lead to nursing home entry?* Washington, DC: U.S. Department of Health and Human Services, Office of Disability, Aging and Long-Term Care. Accessed November 18, 2009 <http://aspe.hhs.gov/daltcp/reports/2007/NHentry.pdf>
- 18 Evercare & National Alliance for Caregiving. (2009, April 28). *The economic downturn and its impact on family caregiving*. Washington, DC: Author.
- 19 Beauchamp, J. & Trebino, L. (2007, March). *Results from the Administration on Aging's third national survey of Older Americans Act program participants* [Final Report submitted to U.S. Department of Health and Human Services]. Washington, DC: Mathematica Policy Research, Inc
- 20 National Alliance for Caregiving and AARP. (2009, November). *Caregiving in the U.S. 2009*. Washington, DC: Author.

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## Prevalence and Economic Value of Family Caregiving, by State (2007)

STATE	STATE POPULATION	NUMBER OF CAREGIVERS	ECONOMIC VALUE (in millions)
Alabama	4,630,000	570,000	\$5,200
Alaska	683,000	74,000	\$1,050
Arizona	6,340,000	610,000	\$6,900
Arkansas	2,830,000	360,000	\$3,500
California	36,600,000	4,000,000	\$48,000
Colorado	4,860,000	540,000	\$6,500
Connecticut	3,500,000	370,000	\$4,900
Delaware	865,000	105,000	\$1,280
District of Columbia	588,000	57,000	\$670
Florida	18,250,000	1,800,000	\$19,200
Georgia	9,540,000	1,330,000	\$13,000
Hawaii	1,283,000	113,000	\$1,450
Idaho	1,499,000	162,000	\$1,600
Illinois	12,850,000	1,490,000	\$17,100
Indiana	6,350,000	720,000	\$7,800
Iowa	2,990,000	300,000	\$3,400
Kansas	2,780,000	270,000	\$2,700
Kentucky	4,240,000	530,000	\$5,400
Louisiana	4,290,000	560,000	\$4,900
Maine	1,317,000	153,000	\$1,840
Maryland	5,620,000	600,000	\$6,600
Massachusetts	6,450,000	690,000	\$8,800
Michigan	10,070,000	1,280,000	\$14,400
Minnesota	5,200,000	590,000	\$7,100
Mississippi	2,920,000	460,000	\$4,000
Missouri	5,880,000	590,000	\$6,300
Montana	958,000	111,000	\$1,140

STATE	STATE POPULATION	NUMBER OF CAREGIVERS	ECONOMIC VALUE (in millions)
Nebraska	1,775,000	177,000	\$2,000
Nevada	2,570,000	280,000	\$3,300
New Hampshire	1,316,000	147,000	\$1,830
New Jersey	8,690,000	980,000	\$11,800
New Mexico	1,970,000	210,000	\$2,100
New York	19,300,000	2,200,000	\$25,000
North Carolina	9,060,000	1,110,000	\$11,600
North Dakota	640,000	56,000	\$580
Ohio	11,470,000	1,320,000	\$14,200
Oklahoma	3,620,000	380,000	\$3,700
Oregon	3,750,000	410,000	\$4,800
Pennsylvania	12,430,000	1,390,000	\$15,600
Rhode Island	1,058,000	114,000	\$1,470
South Carolina	4,410,000	580,000	\$5,700
South Dakota	796,000	87,000	\$920
Tennessee	6,160,000	780,000	\$7,800
Texas	23,900,000	2,800,000	\$26,000
Utah	2,650,000	340,000	\$3,500
Vermont	621,000	55,000	\$680
Virginia	7,710,000	910,000	\$9,200
Washington	6,470,000	640,000	\$7,900
West Virginia	1,812,000	280,000	\$2,500
Wisconsin	5,600,000	590,000	\$6,600
Wyoming	523,000	55,000	\$580
<b>US</b>	<b>302,000,000</b>	<b>34,000,000</b>	<b>\$375,000</b>
<p>Source: Houser, A. &amp; Gibson, M.J. (2008, November). <i>Valuing the invaluable: The economic value of family caregiving, 2008 Update</i>. Washington, DC: AARP Public Policy Institute.</p>			