

Family Caregiving 2010 Year in Review

A compilation of the key developments in research, legislation, program updates, and media coverage affecting family caregivers in 2010.



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National Center on Caregiving

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About Family Caregiver Alliance

Founded in 1977, Family Caregiver Alliance serves as a public voice for caregivers, illuminating the daily challenges they face, offering them the assistance they so desperately need and deserve, and championing their cause through education, services, research and advocacy. Long recognized as a pioneer among caregiver organizations, FCA operates programs at local, state and national levels. In 2001, FCA established the National Center on Caregiving to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country.

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Executive Summary

Family Caregiving 2010: Year in Review for Family Caregivers highlights and summarizes some of the most noteworthy developments in research, legislation, program updates, and media coverage affecting family caregivers, patients, healthcare and service providers, and program administrators in 2010. The majority of the report is not original content and the primary sources are cited and hyper-linked throughout the report.

The Affordable Care Act (ACA) took center stage as one of the most important pieces of healthcare related-legislation ever passed. A number of provisions in the law will improve the support systems for family caregivers and their loved ones. The Caregivers and Veterans Omnibus Health Services Act, enacted in May, will also create an important system of support for caregivers of veterans from wars since September 11, 2001. The year ended on a high note with Congress passing the National Alzheimer's Project Act, though funding for research to find a cure for this disease, recently ranked as the sixth leading cause of death in the U.S., is still wholly inadequate.¹

Legislation was introduced at the state and federal level to better support employed family caregivers with paid family leave programs, job protection for caregivers, and paid sick days that could be used by the employee while caring for a sick family member. At the state level, bills mandated the creation of state plans that addressed the growing number of persons with Alzheimer's, created Lifespan Respite Program Coalitions, and created pilot programs within Medicaid to empower beneficiaries and partially compensate their family caregivers.

Looking forward to 2011, it is imperative that state and federal policymakers continue to incorporate family caregivers who provide the majority of long-term care in their rule-making, budget preparation and implementation of the Affordable Care Act. At the state level, additional cuts or tightening of eligibility requirements to Medicaid appear inevitable (especially for waiver programs and "optional" benefits that are not required by the federal government). Yet, research has consistently demonstrated that Home and Community Based Services (HCBS) that allow individuals to remain in their homes are not only preferred by most people but are also more cost-effective than institutional care.² States will face a difficult job of balancing their budgets while also meeting the requirements of the Americans with Disabilities Act and the *Olmstead* decision.³

¹ According to the US Department of Health and Human Services, Alzheimer's Disease was the sixth leading cause of deaths in 2007. Xu, J., Kochanek, K.D., Murphy, S.L., & Tejada-Vera, B. (2010, May 10). *Deaths: Final Data for 2007*. US Department of Health and Human Services, National Vital Statistics Report. Retrieved from http://www.cdc.gov/NCHS/data/nvsr/nvsr58/nvsr58_19.pdf (As cited on Alzheimer's Association report, "2010 Alzheimer's Disease Facts and Figures, Volume 6")

² AARP South Carolina noted that "average daily net paid claim in 2010 for a South Carolina Medicaid individual participant in a Community Choices waiver program was \$32 compared to \$127 for a nursing home" and "an expenditure of approximately \$600 to \$1,500 per senior may result in a savings of up to \$40,429 (\$12,129 state funds) per senior in Medicaid funded institutional long term care service per year." AARP also points out that the waiting list for HCBS in South Carolina has 4,000 people. AARP South Carolina. (2010, September 15). Home and Community Based Services are Important to Older SC Residents. Retrieved from: http://www.aarp.org/relationships/caregiving/info-09-2010/home_and_community_sc.html

³ In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that under the Americans with Disabilities Act state governments cannot force people with disabilities into institutional care. For a more nuanced explanation, see: Carlson, E., & Coffey, G. (2010, October). *10-Plus Years After the Olmstead Ruling*:

Federal Legislation in the 111th Congress Affecting Family Caregivers

A number of practical, cost-effective pieces of legislation to support family caregivers were introduced in the 111th Congress. However, budget constraints prevented many introduced bills from becoming laws. As the first of the baby-boomers start turning 65 in 2011, the needs of family caregivers may receive greater focus by state and federal policymakers.

The Patient Protection and Affordable Care Act, passed on March 23, 2010, includes demonstrations and pilot programs that will assist caregivers and their loved ones. While the Affordable Care Act is a strong step forward, the law unfortunately did not include an amendment proposed by Senator Amy Klobuchar (D-MN) that would have promoted information and referral services to family caregivers of Medicare beneficiaries and included an assessment of Medicaid beneficiaries' family caregivers.⁴

A number of provisions in the law will support family caregivers:

- The CLASS program is as a new, voluntary long-term services and support insurance program that will assist with paying some of the costs of care if a person needs assistance with activities of daily living. The Secretary of Health and Human Services must designate a program by October 2012. Through the CLASS program, a care recipient could designate that their insurance benefit be used to compensate a family or friend serving as their caregiver.⁵
- In September 2010, Secretary Sebelius announced \$68 million in funding (as part of the Affordable Care Act) for programs to administer support to seniors, individuals with disabilities, and caregivers. The funds will assist consumers to manage Medicare and Medicaid benefits, navigate long-term care options, strengthen counseling at Aging and Disability Resource Centers, and provide consumer assistance with transitions from nursing or rehabilitation facilities.⁶
- The Elder Justice Act was signed into law as part of the Affordable Care Act and authorizes funding for Adult Protective Services, grants for Long-term care ombudsman programs, and establishes an Elder Justice Coordinating Council.⁷

Progress, Problems, and Opportunities. National Senior Citizens Law Center. Retrieved from <http://www.nslc.org/about-us/nslc-in-the-news/NSCLC%20Olmstead%20Report.pdf>

⁴ Family Caregiver Alliance. (2010, January 6). *Senate Passes Health Care Reform Legislation Without Caregiving Amendment*. PolicyDigest, Volume X, Number 1. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2373#federal1

⁵ Professor Richard Kaplan wrote a concise overview of the need for financing long-term care and the challenges that program administrators will face in creating and implementing the CLASS Program. Kaplan, Richard L., (2010, July-August). Financing Long-Term Care After Health Care Reform. *Journal of Retirement Planning*, p. 9. Illinois Program in Law, Behavior and Social Science Paper No. LE10-001. Retrieved from <http://ssrn.com/abstract=1692288>

⁶ Health and Humans Services. (2010). HHS announces new grants and programs from the Affordable Care Act to help people navigate health and long-term care options [Press release]. Retrieved from <http://www.hhs.gov/news/press/2010pres/09/20100927a.html>

⁷ The Elder Justice Coalition (2010). Elder Justice Bills Clear Congress, Obama to Sign into Law [Press release]. Retrieved from http://elderjusticecoalition.com/docs/Elder-Justice-Coalition-March_22_2010.pdf

- Expansion of Home and Community Based Services (HCBS) through Medicaid will allow more people to remain in their homes, including:

Independence at Home demonstration that will allow patients with multiple chronic conditions (who account for 66 percent of all healthcare spending despite representing only 27 percent of the population⁸) to remain in their homes and have medical professionals visit them. This will also alleviate the burden on family caregivers to provide (or secure) transportation to various medical appointments.

State Balancing Incentive Payments program will allow eligible states to compete for up to \$3 billion in enhanced matching payments in exchange for increasing the percentage of Medicaid Long-Term Services and Support expenditures that are spent on HCBS. This program incentivizes states to shift more of their Medicaid long-term care spending to programs that allow individuals to remain in their homes instead of moving to institutional care.

The Money Follows the Person rebalancing demonstration was extended to 2016 with \$450 million allocated for each fiscal year. States are provided additional federal funding to shift their approach of providing long-term and disabled care services to a more “person-centered” model.⁹

Community First Choice Option is a state option that becomes effective in October 2011 and will help fund home and community based attendant services and supports. Participating states will receive a six percentage point increase in their FMAP rate for expenditures in this program.¹⁰

- The Community-Based Care Transitions Program will assist in creating and funding collaborative partnerships between hospitals and community-based organizations in order to meet the goal of implementing evidence-based care transitions services for Medicare beneficiaries who are at high

⁸ U.S. Department of Health and Human Services. Initiative on Multiple Chronic Conditions. Retrieved from <http://www.hhs.gov/ash/initiatives/mcc/index.html>

⁹ U.S. Department of Health and Human Services. (2010). CMS Announces \$2.25 Billion in Grants to Extend Money Follows the Person Rebalancing Demonstration [Press release]. Retrieved from <http://www.hhs.gov/news/press/2010pres/07/20100726a.html> See also: Centers for Medicare and Medicaid Services, Community Services and Supports. Money Follows the Person. Retrieved from https://www.cms.gov/CommunityServices/20_MFP.asp

Note: A February 2011 policy brief explains that Money Follows the Person was originally intended to transition 38,000 people; however, due to a lack of affordable housing and other obstacles, the program has thus far served 9,000. With the extension of this program, eligibility was expanded to include people who have been in institutional care for at least 90 days (excluding Medicare short-term rehabilitation). Kaiser Commission on Medicaid and the Uninsured. (2011, February). *Money Follows the Person: A 2010 Snapshot*. Retrieved from: <http://www.kff.org/medicaid/upload/8142.pdf>

¹⁰ Justice, D. (2010, October 3). *Implementing the Affordable Care Act: New Options for Medicaid Home and Community Based Services*. Scan Foundation. Retrieved from <http://www.thescanfoundation.org/commissioned-supported-work/implementing-affordable-care-act-new-options-medicare-home-and-community> and Families USA. Long-Term Services Health Reform Provisions: Community First Choice Option. Retrieved from <http://www.familiesusa.org/issues/long-term-services/health-reform/community-first-choice-option.html>

risk for hospital readmission.¹¹ Hospital discharges often thrust individuals into a new caregiver role, many times with little to no training for this new responsibility and this can contribute to hospital readmissions. This program has the potential to improve care transitions, reduce hospital readmissions, and better support caregivers.

Implementation of the Affordable Care Act

The Affordable Care Act is being implemented over the course of several years, with many of the most significant provisions being enacted in 2014. Four Web sites designed or funded by foundations and organizations with a healthcare focus provide timely information on the implementation of the Affordable Care Act.

On November 8, 2010, Family Caregiver Alliance, the National Alliance for Caregiving, and the National Family Caregivers Association hosted a Webinar that highlighted provisions within the Affordable Care Act most relevant to family caregivers. The archived Webinar, PowerPoint presentation, Q&A, and other resources, are available at this link: "[*The Impact of Healthcare Reform on Family Caregivers*](#)"

Websites

1) **Statereforum** - This Web site, published by the National Academy for State Health Policy, is designed to support state officials working to implement federal health reform legislation.

2) **Commonwealth Fund Health Reform Resource Center**: This section of Commonwealth Fund's Web site includes an implementation timeline and a "provision finder" tool.

3) **Health Reform Source** is published by the Kaiser Family Foundation and includes a wide variety of information related to implementation of the new law.

4) **Health Reform GPS** is a project of the George Washington University's Hirsh Health Law and Policy Program and the Robert Wood Johnson Foundation and provides timely analysis and updates about the implementation of the law.

¹¹ Coleman, E., Berman, A. (2010, April 29). Improving Care Transitions: A Key Component of Health Reform [Blog posting]. Health Affairs Grant Watch Blog. Retrieved from <http://healthaffairs.org/blog/2010/04/29/improving-care-transitions-a-key-component-of-health-reform/>

Federal Legislation Affecting Family Caregivers

The chart on the following page is hyperlinked to summaries on FCA's Web site. Legislation affecting family caregivers in the 111th Congress included:

Alzheimer's: Four federal bills were introduced, one of which became law, the National Alzheimer's Project Act. While advocates are excited about this legislation that will create a much-needed focus on this disease, there was no additional research funding tied to the legislation. In a 2010 *New York Times* Op-Ed, former Supreme Court Justice Sandra Day O'Connor, a caregiver for her husband with Alzheimer's, noted that for every penny spent by NIH on research of Alzheimer's, \$3.50 is spent on care for patients with Alzheimer's.¹² Additional introduced bills included a requirement for Medicare to pay for Alzheimer's and other dementia diagnosis services; increased funding for the National Institutes of Health to study Alzheimer's disease; creation of a national "Silver Alert" plan; increased grant funding for service providers; and creation of tax credits for caregivers for people with chronic conditions like Alzheimer's.

Another positive development was the Social Security Administration announcing in February 2010 that it would add early-onset Alzheimer's disease to its Compassionate Allowance Initiative, thus allowing for faster payments of benefits for beneficiaries who qualify for Social Security Disability Income (SSDI) or Supplemental Security Income (SSI).¹³ The Senate Special Committee on Aging also held a forum in December 2010 about Alzheimer's disease and its impact on families.¹⁴

Budget: Vice President Biden's "*Caregiver Initiative*" would have provided strong support to caregivers through additional funding in the Senate Appropriations bill for the departments of Labor and Health and Human Services. The funding was projected to provide an additional 1 million more hours of adult day-care, 1.3 million more hours of personal care assistance, and 3 million more hours of respite care. In addition, \$10 million was allocated to the Department of Labor to provide grants to states to help them implement paid leave programs that could support employees who are also caregivers. Unfortunately, the full Senate never voted on this legislation, and the temporary spending bill passed by Congress provided funding for Fiscal Year 2011 at Fiscal Year 2010 levels. This continuing resolution spending bill will be re-visited in February/March 2011.

"The funding was projected to provide an additional 1 million more hours of adult day-care, 1.3 million more hours of personal care assistance, and 3 million more hours of respite care."

¹² O'Connor, S.D., Prusiner, S., & Dychtwald, K. (2010, October 10). The Age of Alzheimer's. *The New York Times*. Retrieved from <http://www.nytimes.com/2010/10/28/opinion/28oconnor.html>

¹³ The Alzheimer's Association. Social Security Disability. Retrieved from http://www.alz.org/living_with_alzheimers_social_security_disability.asp#compassionate

¹⁴ Family Caregiver Alliance. (2010, December 15). *Senate Special Committee On Aging Holds Forum On Alzheimer's Disease*. PolicyDigest, Volume X, Number 23. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2455#federal1

Employed caregivers: Six federal bills were introduced to improve the Family Medical Leave Act. Introduced bills would have lowered the employer threshold to include employers of 25 or more employees (the current threshold is 50); lengthened the recertification period for employees with medication conditions; eliminated the 1,250 hour rule for being eligible for FMLA (but retained the one year requirement); established a state FMLA program; provided grants for states to pay the federal cost of administering wage replacement for individuals taking leave under FMLA; and allowed employees to earn one hour of paid sick time for every 30 hours worked.

Financial support: Five bills were introduced, including legislation that would have: provided a tax credit for family caregivers; provided social security credits for caregivers; created a tax deduction for long-term care insurance premiums; and changed provisions in the bankruptcy code for family caregivers who experienced a dramatic loss of income and/or increased medical expenses because of caregiving.

Medicaid/Medicare: Eight bills were introduced and provisions from five of these eight bills were included in the Affordable Care Act. The other three bills addressed medication reviews, phasing out the Medicare Disability waiting period, and Medicare coverage of substitute adult day care.

National Policy and Call Centers: Four bills were introduced that would have created resource centers affecting caregivers, including: a national resource center on family caregiving; a national center on palliative and end-of-life care at NIH and a 24-hour hotline; a National Alzheimer's Supporting Center and Administration on Aging Alzheimer's call center; and a call center and clearinghouse for advanced directives and end-of-life decision-making.

Veteran's health: *The Caregivers and Veterans Omnibus Health Services Act*, passed on May 5, 2010, will provide important support to family caregivers of veterans, including stipends for family caregivers of veterans, information and training, respite, counseling, and ongoing supportive services. The law will be implemented by the Department of Veterans Affairs, and the law calls for the Secretary of Veterans Affairs to report to the relevant Congressional committees "not later than 180 days after the date of the enactment of this act."¹⁵ The VA also created a Web site with additional information for caregivers of veterans: <http://www.caregiver.va.gov> as well as a toll-free National Caregiver Support Line: 1-855-260-3274. Three other bills related to veterans were introduced, including training for veterans with traumatic brain injury, housing for veterans, and increasing the amount of money injured service members receive.

¹⁵ Caregivers and Veterans Omnibus Health Services Act of 2010, Public Law 111-163. Retrieved from <http://www.gpo.gov/fdsys/pkg/PLAW-111publ163/pdf/PLAW-111publ163.pdf>

Federal Caregiving Legislation in the 111th Congress	Status
Advance Planning and Compassionate Care Act (2009)	Stalled/Some provisions in ACA
Affordable Health Care for America Act (2009)	ACA
Alzheimer's Breakthrough Act (2009)	Stalled
Alzheimer's Family Assistance Act (2009)	Stalled
Alzheimer's Treatment and Caregiver Support Act (2009)	Stalled
Americans Giving care to Elders (AGE) Act (2009)	Stalled
Caregiver Assistance and Relief Effort (CARE) Act (2010)	Stalled
Caregiver Assistance and Resource Enhancement (CARE) Act (2009)	VA
Caring for an Aging America Act (2009)	Stalled
Community Choices Act (2009)	Stalled
Community Coalitions for Access and Quality Improvement Act (2009)	Stalled
Community Living Assistance Services and Supports Act (CLASS) Act (2009)	ACA
Confidence in Long-Term Care Insurance Act (2009)	Stalled
Disabled Veteran Caregiver Housing Assistance Act (2009)	Stalled
Elder Caregiver Support and Information Enhancement Act (2009)	Stalled
Empowered at Home Act (2009)	Stalled
Ending the Medicare Disability Waiting Period Act (2009)	Stalled
Family and Medical Leave Enhancement Act (2009)	Stalled
Family and Medical Leave Restoration Act (2009)	Stalled
Family Caregiver Program Act (2009)	VA
Family Fairness Act (2009)	Stalled
Family Leave Insurance Act (2009)	Stalled
FIRST Act (2009)	Stalled, but some aspects included in Senate Appropriations bill
FY2009 Omnibus Appropriations (2009)	Enacted
Geriatrics Loan Forgiveness Act (2009)	Stalled
Healthy Families Act (2009)	Stalled
Heroes at Home Act (2009)	VA
Home Healthcare Nurse Promotion Act (2009)	Stalled
Independence at Home Act (2009)	ACA
Medical Bankruptcy Fairness Act (2009)	Stalled
Medicare Adult Day Care Services Act (2009)	Stalled
Medicare Care Transitions Program Act (2009)	ACA
Medicare Transitional Care Act (2009)	ACA
National Alzheimer's Project Act (2009)	Enacted
National Defense Authorization Act (2009)	Enacted, (Two amendments affecting veteran caregivers were attached to this larger bill)
National Silver Alert Act (2009)	Stalled
Patient Protection and Affordable Care Act (2009)	ACA
Project 2020: Building on the Promise of Home and Community-Based Services Act (2009)	Stalled
RE-Aligning Care Act Act (2009)	Stalled
Retooling the Healthcare Workforce for an Aging America Act (2009)	Stalled
Senior Navigation and Planning Act (2009)	Stalled
Social Security Caregiver Credit Act (2009)	Stalled
Support Goals of Senior Caregiving (2009)	Passed
Veteran and Servicemember Caregiver Support Act (2009)	VA
Veterans' Caregiver and Omnibus Health Benefits Act (2009)	VA
Wounded Warrior Project Family Caregiver Act (2009)	VA

Note: Laws are hyper-linked to summaries on FCA's Web site.

Source: FCA Web site and U.S. Library of Congress- Thomas (www.thomas.gov)

ACA = Similar provisions were included in Affordable Care Act.

VA = Similar provisions were included in the Caregivers and Veterans Omnibus Health Services Act.

Stalled = Legislation did not pass in the 111th Congress.

State Legislation

Family Caregiver Alliance monitored 44 state bills that were introduced during the 2009/2010 legislative sessions. Budget constraints meant that just over a third of the bills passed (15 were enacted while 29 bills stalled).

Alzheimer's: Introduced legislation focused on funding, outreach, education, and creating task forces to create state-level plans to address Alzheimer's disease. The Alzheimer's Association also tracked legislation on "Silver Alerts," (amber alerts for people who wander); state Alzheimer's plans, and state adoption of the Uniform Adult Guardianship and Protective Proceedings Jurisdiction Act.¹⁶

Awareness and Support: Several bills addressed increasing outreach, awareness, and assessments of family caregivers and increased funding for programs supporting family caregivers. For example, Texas created a caregiver assessment to be administered to caregivers through its Medicaid long-term services and support programs.¹⁷

Employment: Support for employed family caregivers was included in 15 pieces of legislation in 10 states. Legislation addressed family and medical leave, familial status protection (caregiver would be a protected classification) and providing paid sick days that could be used for an ill employee or for an employee to provide caregiving for an ill relative.

Financial Support: Caregiving can be financially draining, especially if a caregiver is forced to reduce or discontinue employment. Two bills were introduced (and a pilot was enacted in IL¹⁸) to allow Medicaid beneficiaries to partially compensate spouses or other family caregivers. Three other states introduced bills that would have provided a tax credit for caregivers, provided increases in grants available for home modifications, and increased grants available to family caregivers for out-of-pocket expenses.

¹⁶ Alzheimer's Association. State Legislation. Retrieved from http://www.alz.org/join_the_cause_state_legislation.asp For additional information about state adoption of the Silver Alert, see: National Association of States United for Aging and Disabilities (2010, November 9). *Silver Alert Initiatives in the States*. Retrieved from http://www.nasuad.org/documentation/nasuad_materials/Silver%20Alert%20Updated%20Report_11-9-10.pdf

¹⁷ Senate Bill 271, enacted 6/19/2009. See: Texas Department of Aging and Disability Services. (2010, August). *Rider 38. Delivery of Caregiver Support Services*. Retrieved from http://www.dads.state.tx.us/news_info/publications/legislative/Rider38Report-8-10.pdf

¹⁸ Illinois Public Act 096-0351, Enacted on 8/13/2009. Retrieved from <http://www.ilga.gov/legislation/BillStatus.asp?DocTypeID=HB&DocNum=39&GAID=10&SessionID=76&LegID=39982>

State Budgets: The Recovery Act provided states with additional FMAP funding from the federal government to help pay for Medicaid which experienced higher enrollments because of the economic down-turn. This funding was originally set to expire at the end of 2010, however, it was extended (at a lower level) until June 2011. After June 2011, states will be forced to pick up a larger percent of the Medicaid bill and as a result, may continue to increase cost-sharing for Medicaid recipients, limit services, and stop providing optional services, most of which will have negative impacts on family caregivers and their loved ones. In Arizona, the legislative liaison for the state Medicaid program predicted that without the extra FMAP funding, Arizona's Medicaid program will face a \$1 billion shortfall starting July 1, 2011.¹⁹

Even with the additional federal funding, almost all states struggle to afford Medicaid:

- Eighteen states reported implementing utilization controls and other reductions on long-term care services in FY 2010 to contain costs.²⁰
- Forty-eight states implemented at least one new policy to control costs in fiscal year 2010 and 46 states plan to also implement cost containment policies in FY 2011.²¹
- Since 2008, healthcare services were cut in 31 states, in addition, 29 states and the District of Columbia also cut services to the elderly and disabled.²²
- Fifteen states reported budget gaps halfway through FY 2011, the sum of these shortfalls is estimated at \$26.7 billion.²³
- As of November 25, 2010, eighteen states reported that Medicaid or other healthcare programs were over budget for FY 2011.²⁴

The Center on Budget and Policy Priorities issued a [report](#) in November 2010 about cuts that states had made to a number of programs. Some of the cuts from the report that are especially relevant to caregivers are highlighted below:

- **Alabama** has ended homemaker services for approximately 1,100 older adults. These services often allow people to stay in their own homes and avoid nursing home care.
- **Arizona** state policymakers, facing a \$1.5 billion budget shortfall, decided to stop covering transplants for patients in its Medicaid program.²⁵

¹⁹ Gonzalez, Angela. (2010, October 11). Arizona Medicaid Faces \$1 billion shortfall. *Phoenix Business Journal*. Retrieved from <http://www.bizjournals.com/phoenix/stories/2010/10/11/story4.html>

²⁰ Smith, V.K., Gifford, K., Ellis, E., Rudowitz, R., & Snyder, L. (2010, September). Hoping for Economic Recovery, Preparing for Health Reform: A Look at Medicaid Spending, Coverage and Policy Trends Results from a 50-State Medicaid Budget Survey for State Fiscal Years 2010 and 2011.

Health Management Associates and Kaiser Commission on Medicaid and the Uninsured, Kaiser Family Foundation. Retrieved from <http://www.kff.org/medicaid/8105.cfm>

²¹ Ibid.

²² Johnson, N., Oliff, P., & Williams, E. (2010, November 5). An Update on State Budget Cuts: At Least 46 States Have Imposed Cuts That Hurt Vulnerable Residents and the Economy. Center on Budget and Policy Priorities. Retrieved from <http://www.cbpp.org/cms/index.cfm?fa=view&id=1214>

²³ National Conference of State Legislatures. (2010, December 7). State Budget Update: November 2010. Retrieved from <http://www.ncsl.org/?TabId=21829>

²⁴ Ibid.

²⁵ Robbins, T. (2010, November 17). Arizona Budget Cuts Put Organ Transplants At Risk. *National Public Radio*. Retrieved from <http://www.npr.org/2010/11/11/131215308/arizona-budget-cuts-put-organ-transplants-at-risk>

- **Connecticut:** Because of changes the state made to its Medicaid program, on June 1, 2010, over 220,000 pregnant women, parents, caretaker relatives and disabled and elderly adults lost coverage for over-the-counter medications and nutritional supplements (with exceptions for insulin and supplies, nutritional supplements for those with feeding tubes, and prenatal vitamins).
- **Georgia** has reduced such programs for the elderly as services for people with Alzheimer's Disease, elder service centers, prescription drug assistance, and elder support, including a recent cut of 5 percent in the FY 2011 budget.
- **Kansas** has reduced grants to Centers for Independent Living, resulting in a loss of services for nearly 2,800 individuals with a disability.
- **Massachusetts** cut funding for the state's elder home care program by 5 percent in its FY2011 budget. The program allows elderly residents to receive long-term care in their community rather than a nursing home. This cut could result in more than 1,000 elderly residents losing access to care.
- **Michigan** froze enrollment for long term care services and supports that help the developmentally disabled avoid institutionalization, resulting in 300 people with developmental disabilities being placed on a waiting list.
- **Minnesota** has capped enrollment at current levels for a program that provides expanded health services and care coordination for people with disabilities. The state has also restricted enrollment in or scaled back a number of programs that allow the elderly and disabled to receive services in their home that they might otherwise only be able to receive in a nursing home, hospital, or other institution. As a result, thousands of elderly and disabled Minnesotans will see their access to these services denied or significantly reduced.
- **South Carolina** eliminated a program that helps seniors pay for prescription drug costs not covered by Medicare part D.²⁶

²⁶ Johnson, N., Oliff, P., & Williams, E. (2010, November 5). An Update on State Budget Cuts: At Least 46 States Have Imposed Cuts That Hurt Vulnerable Residents and the Economy. Center on Budget and Policy Priorities. Retrieved from <http://www.cbpp.org/cms/index.cfm?fa=view&id=1214>

State Legislation	Status
AR - Alzheimer's Disease Task Force (2009)	Enacted
AZ - Family and Medical Leave Insurance (2009)	Stalled
AZ - Family Leave Insurance (2010)	Stalled
CA - Familial Status Protection (2009)	Stalled
CA - Job Protection (2009)	Stalled
CA - Paid Sick Days (2009)	Stalled
CO - Healthy Families and Workplaces Act (2010)	Stalled
CT - Paid Sick Days (2010)	Stalled
CT - Unpaid Leave for Family Caregivers of Servicemembers (2009)	Enacted
DE - Adult Abuse Registry (2009)	Enacted
HI - Data Collection on Employed Caregivers (2009)	Enacted
HI - Extending Joint Legislative Committee on Aging in Place (2010)	Enacted
HI - Family Leave Provisions and Data Collection (2009)	Stalled, but HB 982 was enacted.
IL - Kinship Navigator (2009)	Enacted
IL - Medicaid Home Care Pilot for Spousal Caregivers (2009)	Enacted
MA - Paid Family and Medical Leave (2009)	Stalled
ME - Expanding Long-Term Care Services (2009)	Enacted
ME - Family Caregiver Anti-Discrimination (2009)	Stalled
MN - Establish Alzheimer's Disease Working Group (2009)	Stalled, but HF 1760 passed.
MN - Lifespan Respite Program (2009)	Stalled
MO - Alzheimer State Plan Task Force (2009)	Enacted
MO - Pilot Program Paying Family Caregivers (2009)	Stalled
NH - Family Leave Insurance	Stalled
NY - Adult Day Respite Demonstration Programs (2009)	Stalled
NY - Alzheimer's Disease Outreach and Education (2009)	Stalled
NY - Behavioral Health, Chemical Dependency and Long-term Care Act (2009)	Stalled
NY - Caregiver's Assistance Act (2009)	Stalled
NY - Caregiving Expenses Tax Credit (2009)	Stalled
NY - Consumer Directed Home Care Demonstration (2009)	Stalled
NY - Employed Family Caregivers Program (2009)	Stalled
NY - Funding for Alzheimer's Disease Resources (2009)	Stalled
NY - Grandparent Caregivers Support Program (2009)	Stalled
NY - Paid Family Leave (2009)	Stalled
NY - Respite Care Demonstration	Stalled
OR - Health Reform (2009)	Enacted
OR - Paid Family Leave Insurance (2009)	Stalled
PA - Expand Family Caregiver Support Program (2009)	Stalled
PA - Family Caregiver Support Advisory Board (2009)	Stalled
PA - Family Caregiving Reimbursement Increase (2009)	Stalled
TX - Family Caregiver Information and Outreach and Guardianship (2009)	Enacted
TX - Family Caregiving Public Awareness (2009)	Stalled
TX - Lifespan Respite Program (2009)	Enacted
TX - Strengthening Delivery of Informal Caregiver Support Services (2009)	Enacted

Note: Laws are hyper-linked to summaries on FCA's Web site.

Source: FCA Web site and state legislature Web sites

Stalled = Legislation did not pass in the 2009/2010 state session.

Research on Medicaid

Medicaid is especially relevant to family caregivers and care receivers because it often becomes the de-facto funder of long-term care once people have exhausted most of their assets. Home and Community Based Services (HCBS), are administered through Medicaid Waivers and 48 states currently operate 300 waivers.²⁷ States are granted a great deal of flexibility in administering their Medicaid programs and researchers have focused on these differences to assess how various policies affect healthcare coverage and state budgets. In 15 states, a friend or family member of a Medicaid beneficiary can be partially compensated for providing care.²⁸

Research on Medicaid Policies, Payment Practices, and Financing of Medicaid

1) "The Best and Worst State Practices in Medicaid Long-Term Care"

This April 2010 policy brief, written by Dr. Candace Howes and released by the Direct Care Alliance, explains why Medicaid policies lead to so much variation in current state Medicaid long-term care programs, and how those policies have been used in some states to expand the range and availability of services. It also draws lessons from innovative states to suggest reforms in national Medicaid policies that would make home- and community-based services accessible to more program participants. The brief provides information about each state's coverage of long-term care services and the amount of spending per recipient on HCBS versus nursing homes. For more information, visit: [Direct Care Alliance "The Best and Worst State Practices in Medicaid Long-Term Care"](#)

2) LTC Generosity Index Used To Explain Variation In Medicaid Spending

A paper by professors from the Health Policy Research Center at the University at Albany, State University of New York, discusses the difficulty for state policymakers in assessing how state Medicaid policy is connected to overall state Medicaid spending. There is enormous variation in state Medicaid programs, for example, the authors explain that in Connecticut, 86 out of 1,000 elderly people have Medicaid-financed nursing home care, while in New Jersey only 48 out of 1,000 elderly people receive this type of care. The authors first analyze the generosity of coverage in terms of what populations and services are covered with the assumption that more generous states would spend more on long-term care services. However, the authors find that "service and coverage generosity are only moderately correlated (.44) with overall per capita long-term care spending..." They suggest that other variables may weaken the explanatory power, for example, a state may have generous policies but difficult application or spend-down policies may discourage enrollment. The second variable examined is the rates paid for particular services, based on the assumption that higher rates would mean higher state expenditures; however, this variable was not perfectly correlated with spending either. The authors use a previously designed "Long-Term Care Policy Generosity Index" that combines eight

²⁷ *The ADA and Olmstead Enforcement: Ensuring Community Opportunities for Individuals with Disabilities*: Hearings before the Committee on Health, Education, Labor and Pensions. United States Senate. 111th Cong., (2010). (testimony of Cynthia R. Mann, J.D., Director, Center for Medicaid & State Operations, Centers for Medicare & Medicaid Services). Retrieved from <http://www.hhs.gov/asl/testify/2010/06/t20100622a.html>

²⁸ Cash and Counseling Web site. Please note, there are additional eligibility criteria in addition to qualifying for Medicaid, some programs have waiting lists, and this information may change based on state budget situations. Retrieved from <http://www.cashandcounseling.org/>

variables. Using this index, the authors are able to "explain" two-thirds of the variation in long-term care spending across the states. New York is rated the most generous using this index while Nevada is rated least generous. For more information, visit:

[*Health Policy Research Center: "Medicaid Policy and Long-Term Care Spending"*](#)

3) "Access to Long-Term Services and Supports: A 50-State Survey of Medicaid Financial Eligibility Standards"

The Public Policy Institute at AARP released a report that compiled state Medicaid financial eligibility standards for nursing home and home and community-based waivers services for older person and adults with disabilities. The report explains differences in how states treat assets and income both before and after qualifying for Medicaid. For more information, visit: [*AARP: "Access to Long-Term Services and Supports: A 50-State Survey of Medicaid Financial Eligibility Standards"*](#)

4) "Long-Term Care Fundamentals: The Financing of Long-Term Care"

The Scan Foundation provided an overview of the financing of long-term care in California, and while the report includes California-specific data, many of the issues discussed are applicable to all states. Medicaid pays the largest share of long-term care nationally, funding 40 percent of care provided in 2008. The authors cite a recent poll in which more than two-thirds of Californians aged 40 and older incorrectly thought that Medicare is the primary payer of long-term care. Medicare does not generally pay for long-term care, but will pay for post-acute care services, including short-term home care or home healthcare for rehabilitation after a hospital stay. The report explains that approximately 36 percent of long-term care is paid for through either long-term care policies or "out-of-pocket" expenditures, and that many Americans also receive assistance from friends or family. For more information, visit: [*Scan Foundation: "Long-Term Care Fundamentals No. 3: The Financing of Long Term Care"*](#)

"Medicaid pays the largest share of long-term care nationally, funding 40 percent of care provided in 2008."

5) Three Papers on Medicaid Long-Term Services and Supports

The Center for Health Care Strategies released three documents as part of their *Innovations in the Medicaid Continuum of Care* series that was developed to help state and federal policymakers identify high-quality and cost-effective strategies for addressing the full range of clinical and long-term supports and services (LTSS) needs of Medicaid beneficiaries. For more information, visit:

- A. [*"Systems of Care: Environmental Scan of Medicaid-Funded Long-Term Supports and Services"*](#)
- B. [*"Medicaid-Funded Long-Term Support and Services: Snapshots of Innovation"*](#)
- C. [*Medicaid-Funded Long-Term Care: "Toward More Home and Community Based Options"*](#)

6) "Weighing Public and Private Options for Reforming Long-Term Care Financing: Findings from a National Survey of Specialists"

A supplement to the August issue of *Medical Care Research and Review* featured results from the Commonwealth Fund's survey of long term care specialists around financing of long-term care. Two-thirds of the respondents ranked financing reform as one of the top three challenges facing long-term care. For more information, visit:

[*The Commonwealth Fund: "Weighing Public and Private Options for Reforming Long-Term Care Financing: Findings from a National Survey of Specialists"*](#)

7) Report on Medicaid Payment Practices As Program Expands

A report from the Center for Health Care Strategies addresses current Medicaid payment practices in the context of Medicaid growing to become the nation's single largest insurer by 2016, with an estimated 20 million additional beneficiaries. According to the authors, the Centers for Medicare and Medicaid have provided somewhat limited guidance and stakeholders have therefore turned to the courts to interpret federal statutory mandates, which can be a cumbersome and time-consuming process. The authors examine several of these court cases and conclude by suggesting that Medicaid will have to become a more sophisticated purchaser of healthcare (for example, by better leveraging its market position) as the number of beneficiaries increases. A recent *USA Today* article profiled some of the nation's largest Medicaid health plans whose leaders hope to expand under the Affordable Care Act. However, many patients and doctors interviewed in the article complained about difficulties finding doctors in their networks, low reimbursement rates and long waits for specialists. For more information, visit:

[*Center for Health Care Strategies: "Medicaid Payment Reform: What Policymakers Need to Know About Federal Law"*](#)
[*USA Today "Medicaid Managed Care Programs Grow; So Do Issues"*](#)

8) Report Profiles Performance Measures In Fee-For-Service Medicaid

A report from the Center for Health Care Strategies, Inc examines how nine states have developed performance measurements for their Medicaid fee-in-service (FFS) programs, whose beneficiaries account for approximately 80 percent of total Medicaid spending. The authors explain that the passage of the Affordable Care Act increases the importance of states having the ability to measure healthcare quality for current Medicaid beneficiaries as well as the millions more that will become eligible in 2014. For more information, visit:

[*The Center for Health Care Strategies, Inc: "Performance Measurement in Fee-for-Service Medicaid: Emerging Best Practices"*](#)

9) Health Affairs Focuses on Long-Term Services and Supports

The January 2010 issue of *Health Affairs* (Volume 29, Number 1) focuses on "Advancing Long-Term Services and Supports." It includes articles on how the long-term care (LTC) system functions in the U.S., challenges for delivering long-term services and support, LTC legislation, and issues related to private and public LTC coverage. In addition, various articles focus on patient transition into and out of skilled nursing facilities, improving quality of care, end-of-life care, and the long-term care workforce. One article specifically focused on family caregivers is "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care" by Carol Levine, Deborah Halper, Ariella Peist and David Gould. For more information, visit: [*Health Affairs: "Bridging Troubled Waters: Family Caregivers, Transitions, and Long-Term Care"*](#)

State-level Medicaid Program and Legal Developments

1) Maryland: State Settles Class-Action Lawsuit over Medicaid Calculations

The State of Maryland agreed to pay \$16 million to nursing homes and nursing home residents as part of a settlement around how the state calculated Medicaid recipients' ability to pay for their care. Attorneys argued that the state incorrectly assessed residents' income by not including debt incurred by Medicaid recipients while they lived in a nursing home awaiting a determination of their eligibility for Medicaid. For more information, visit: [Washington Post: "Md. begins paying \\$16 million to settle nursing home lawsuit"](#)

2) New York: Lieutenant Governor's Report Advocates Changes to Medicaid

The Lieutenant Governor of New York, Richard Ravitch, released a report in September 2010 about New York's Medicaid program that consumes approximately one-third of the state budget. His report analyzes a number of issues that he suggests lead to fragmentation of services and high costs for the state. For example, New York is rare among major states for allowing the legislature to set Medicaid reimbursement rates each year as part of budget negotiations. In addition, New York has used flexibility in the Medicaid program to start optional programs and receive a federal match for these programs (FMAP); however, it only receives a 50 percent match from the federal government because of its high average per-capita income. The Lieutenant Governor advocates a number of changes, including consolidating decision-making for Medicaid, advocating for a larger FMAP match, and cost-containment. For more information, visit: [Lieutenant Governor's Report on Controlling Increases in the Cost of New York Medicaid](#)

3) Oregon: Lawmakers Restored Funding to Caregiving Programs

Lawmakers in Oregon voted to restore funding to several programs which serve older and disabled adults and children with disabilities. Oregon Governor Ted Kulongoski had proposed a budget that would have eliminated Oregon Project Independence and the Medicaid Personal Care Programs while also reducing Oregon's In-Home Care Program. Instead, lawmakers shifted funding within the Department of Human Services to continue these programs. For more information, visit: [Oregon Public Broadcasting: "Restored Funding a Temporary Fix But Still Leaves Gaps"](#)

4) Texas: State Legislators Suggest Dropping Medicaid

A November 2010 *Kaiser Health News* article discussed a suggestion by some Texas state legislators to have Texas drop out of Medicaid. While the legal and practical matters are unclear, Republican representatives (who now have a majority in the Texas House Chamber) say they are motivated by an estimated \$25 billion state budget deficit and stringent federal rules about how Medicaid is administered. They also suggest that if Texas drops Medicaid, then low-income people would be able to enroll into state exchanges slated to begin operating in 2014. There are 3.6 million Texans enrolled in Medicaid and seven out of ten Texas nursing home residents rely on Medicaid to pay for their care. Even with restrictive income limits, the biennial bill for Medicaid in Texas is \$45 billion (representing 20 percent of the state budget), of which the federal government pays 60 percent of the bill. The authors explain that almost a dozen other states (including AL, MS, WA, WY) are also considering either dropping Medicaid or remaking it with only state financing and/or seeking federal waivers to change parts of their Medicaid programs. For more information, visit:

Kaiser Health News: "States' Woes Spur Medicaid Drop-Out Talk"

Home and Community Based Services State Developments

Home and Community-Based Services (HCBS) allow more Medicaid beneficiaries to remain in their homes and receive care in a community setting instead of receiving institutional care. The 1999 Supreme Court decision in *Olmstead v. L.C.* put additional pressure on states to comply with the Americans with Disabilities Act through providing HCBS instead of institutional care.²⁹ Demonstration and Medicaid Waiver programs, including the Money Follows the Person Rebalancing Demonstration (extended until 2016), have given states additional tools and incentives to shift more funding to HCBS instead of institutional care.

Despite this progress, the National Senior Citizens Law Center noted in their 2010 report that Medicaid still has a bias towards institutional care because it is an entitlement under federal Medicaid law whereas HCBS is provided in most cases through waivers with limited enrollments and expenditure caps. In addition, Medicaid coverage for HCBS does not include financial support for room and board, whereas these costs are included in Medicaid's payment for nursing home care.³⁰ Finally, AARP recently noted that many HCBS programs are in danger of being reduced or eliminated in light of their "optional" nature (not required by Federal Medicaid law) and continued state budget strains.³¹

"...during the past ten years Medicaid expenditures for community-based services increased from a national average of 27 percent of total Medicaid long-term care (LTC) expenditures to almost 45 percent and that more than half of all Medicaid LTC beneficiaries receive services in community settings."

²⁹ American Public Human Services Association. (2010, August). *Community Integration for People with Disabilities: The Role of Long-Term Care and the Medicaid Buy-in*. Retrieved from http://cwg.aphsa.org/home/docs/CWD_BriefonMedicaid_LTC.pdf

³⁰ Carlson, E., & Coffey, G. (2010, October). *10-Plus Years After the Olmstead Ruling: Progress, Problems, and Opportunities*. National Senior Citizens Law Center. Retrieved from <http://www.nslc.org/about-us/nslc-in-the-news/NSCLC%20Olmstead%20Report.pdf>

³¹ Walls, J., Gifford, K., Rudd, C., O'Rourke, R., Roherty, M., & Copeland, L. (2011, January). *Weathering the Storm: The Impact of the Great Recession on Long-Term Services and Supports*. AARP Public Policy Institute. Retrieved from http://assets.aarp.org/rgcenter/ppi/ltc/CURRENT__Budget_Paper_v9Jan6.pdf

In congressional testimony, Cynthia R. Mann, the Director of the Center for Medicaid & State Operations noted that during the past ten years Medicaid expenditures for community-based services increased from a national average of 27 percent of total Medicaid long-term care (LTC) expenditures to almost 45 percent and that more than half of all Medicaid LTC beneficiaries receive services in community settings. However, Mann also noted: "The percent of Medicaid long-term care funding directed toward HCBS varies among States from 14 to 75 percent."³²

1) CMS Increases Flexibility in Providing Home and Community Based Services

Cindy Mann, the Medicaid Center Director, sent a letter to state Medicaid directors on August 6th, informing them that under the Affordable Care Act (ACA), states have increased flexibility for offering home and community-based services (HCBS) through Medicaid. Specific changes include giving states the ability to provide HCBS to individuals who have not met an institutional level of care. In addition, states will have the option to provide services to individuals with income up to 300 percent of the Supplemental Security Income (SSI) Federal benefit rate (FBR). The new and revised provisions took effect October 1, 2010. To read the letter sent to states, visit:

[Centers for Medicare & Medicaid Services "Re: Improving Access to Home and Community-Based Services"](#)

2) Four Options to Expand Community-Based Care under ACA

A policy brief by the National Academy of State Health Policy analyzes four options within the Affordable Care Act for states to enhance long-term services and supports (LTSS) through Medicaid Home and Community Based Services.

- *State Balancing Incentive Payments Program* will allow eligible states to compete for up to \$3 billion in enhanced matching payments in exchange for increasing the percentage of Medicaid LTSS expenditures on home and community based services (HCBS).
- *Money Follows the Person Rebalancing Demonstration* was extended to 2016. Fourteen states sent letters of intent to apply for this demonstration and each of these states received a \$200,000 planning grant.
- *1915(i) State Plan HCBS* encompasses many services, however, only a few states have adopted this option and the authors suggest that few will adopt this option in the near future because of restrictive provisions.
- *Community First Choice Option* finances HCBS and would provide states a six percentage point increase in their FMAP rate for Community First Choice Option expenditures. The September/October issue of the Commonwealth Fund's *States in Action* also provides additional articles about changes to LTSS as well as examples of how three states are shifting to more patient-centered models within facility based care.

For more information, visit:

[National Academy for State Health Policy: "Implementing the Affordable Care Act: New Options for Medicaid Home and Community Based Services"](#)
[Commonwealth Fund: "States in Action" September/October 2010](#)

³² *The ADA and Olmstead Enforcement: Ensuring Community Opportunities for Individuals with Disabilities*: Hearings before the Committee on Health, Education, Labor and Pensions. United States Senate. 111th Cong., (2010). (testimony of Cynthia R. Mann, J.D., Director, Center for Medicaid & State Operations, Centers for Medicare & Medicaid Services). Retrieved from <http://www.hhs.gov/asl/testify/2010/06/t20100622a.html>

3) Review of Progress since Olmstead Ruling

The National Senior Citizens Law Center released a report in September 2010 focused on the progress that has been made since the landmark *Olmstead* decision. The authors explain that while there have been some positive developments in the creation of programs to shift towards more community-based care, there is also considerable room for improvement. After a review of some of the litigation against states for violating ADA, the authors conclude by explaining the many challenges that still exist in accessing HCBS and provide recommendations. The U.S. Department of Justice also lists briefs related to alleged violations of Title II of the American Disabilities Act on its Web site. For more information, visit: [National Senior Citizens Law Center "10-Plus Years After the Olmstead Ruling: Progress, Problems, and Opportunities."](#)
[U.S. Department of Justice ADA Title II Briefs](#)

4) Review of State Disability Policies since Passage of Americans with Disabilities Act

The Council of State Governments released a report in July 2010 that provides a broad sampling of how states have improved policies to better meet the goals of the Americans with Disabilities Act. The report provides 149 examples of policy changes in 31 states, including Vermont, which was able to shift its Medicaid long-term care spending from 88 percent going to nursing home care in 1996 to only 68 percent in 2006 while the remaining 32 percent paid for HCBS. In Washington state, "...in 2007, more than twice as many people are served under the Medicaid waiver programs for seniors and the disabled persons as are in nursing homes." For more information, visit: [Council of State Governments- "A Survey of State Disability Policy, 2010"](#)

5) Arizona: Court Order Issued in Medicaid HCBS Class Action Case

A court order was issued in March 2010 in a long-running Medicaid class action law suit in Arizona affecting home and community-based services. A U.S. District Court Judge ruled that Arizona's Medicaid program failed to follow the court's prior orders by not implementing a statewide hotline for beneficiaries to report gaps in critical home care services and by failing to require its program contractors to have backup workers on call to substitute for times when a gap in critical services occurs. The original class action lawsuit, filed in 2000, alleged that the Arizona Health Care Cost Containment System (AHCCCS) was not providing consumers with adequate home and community-based services that make it possible to live in the community rather than be forced into a nursing home. For more information, visit: [PHI: "Court Rules on Adequacy of AZ Home and Community-Based Services"](#)

6) Massachusetts: Governor Expands Home and Community-Based Pilot Program

In April 2010, Massachusetts Governor Deval Patrick announced that his administration would expand a pilot program that provides free counseling to older adults about alternatives to nursing home care. While the legislature approved expansion of this program in 2009 and authorized \$2.5 million in funding, the state administration delayed in releasing the funds. The program is credited with keeping more than 300 people in their homes and out of expensive nursing homes in one year. For more information, visit: [Boston Globe: "Program for elderly will be expanded"](#)

7) Missouri: CMS Sanctioned State for Restricting Home Health Eligibility

In February 2010, The Centers for Medicare and Medicaid Services (CMS) sanctioned Missouri's Department of Social Services for requiring that consumers be "confined to the home" to qualify for Medicaid-covered home health services. CMS explains that such a requirement violates the Supreme Court's *Olmstead* decision, which allows people with disabilities to receive services in community settings rather than institutional settings when appropriate, and that people should not lose their home health services just because they leave their home for short periods of time. For more information, visit: *PHI: "Missouri Medicaid Tries to Restrict Home Health Eligibility"*

Medicare

1) AARP Report on Caregivers of Medicare Beneficiaries

AARP analyzes data from the National Long-Term Care Survey, a nation-wide survey of Medicare beneficiaries age 65 and older to compare caregiving trends from 1994 to 2004. Women continued to do the majority of caregiving work in 2004, with wives representing 57 percent of all caregiving spouses and daughters representing almost two-thirds of caregiving children in both 1994 and 2004. For more information, visit:

AARP: "Trends in Family Caregiving and Paid Home Care for Older People with Disabilities in the Community: Data from the National Long-Term Care Survey"

2) Reports Analyze High Medicare Spending for Long-Term Care Beneficiaries

Kaiser Family Foundation released three reports focused on the high use of hospital and other Medicare-covered services for beneficiaries living in nursing homes and other long-term care facilities. The first report analyzes data from 2006 and found that the 2.2 million Medicare beneficiaries living in a long-term care facility represented approximately six percent of the Medicare population but accounted for 17 percent of total Medicare spending. The second report uses interviews with family members and clinical staff at long-term care facilities to identify ten primary reasons for high hospital admission rates among long-term care residents. The third report addresses current financial incentives that may encourage skilled nursing facilities to transfer patients to hospitals. For more information, visit: *Kaiser Family Foundation: "Briefing Examines High Medicare Spending for Beneficiaries in Long-Term Care"*

Title III Programs, Aging and Disability Resource Centers, and National Lifespan Respite Program

In addition to Medicaid/Medicare, one of the largest sources of funding and support for family caregivers and their loved ones is through Title III programs that are funded and authorized by the Older Americans Act. Aging and Disability Resource Centers also connect family caregivers with the support they need as they navigate long-term services and support. The National Lifespan Respite Program, created in 2006, but not funded until Fiscal Year 2009, provides funding for states to create/improve respite options for caregivers of children or adults regardless of special need.³³

³³ ARCH National Respite Network and Resource Center Web site. Retrieved from <http://www.archrespite.org>

1) Increased Demand for Services in Title III Programs

Title III programs are authorized by the Older Americans Act and provide services to seniors in every state, including home-delivered meals, transportation services, and support for caregivers. The agencies are funded through several sources, and of the 64 agencies that responded to a recent GAO survey, 69 percent reported that their state funding was reduced for fiscal year 2010.

The authors of the report also found state agencies administering these programs are facing increased demand for services and are unable to meet all requests for services. In addition, nearly one in five respondents (19 percent) reported that they were generally or very unable to serve all seniors who requested home-delivered meals. Respite programs, funded by Title III E, were the most requested service in FY 2009. However, 27 percent of responding agencies that provide respite reported that they were generally or very unable to meet all requests for respite care. The Older Americans Act is set to be re-authorized in 2011 and the Administration on Aging has a Web site for input on the reauthorization. Family Caregiver Alliance strongly encourages anybody who uses or administers Title III programs to provide feedback to the Administration on Aging through this Web site. For more information, visit:

United States Government Accountability Office: "Older Americans Act: Preliminary Observations on Services Requested by Seniors and Challenges in Providing Assistance"
Administration on Aging Older Americans Act Reauthorization Page

2) Field Hearings on Reauthorization of Older Americans Act

The United States Senate Special Committee on Aging held field hearings in August and September about the Older Americans Act that is expected to be re-authorized in 2011. One of the witnesses, Dorothy Williams, is a caregiver in Wisconsin and explained how the National Family Caregiver Support Program allowed her to receive respite from caring for her mother who has dementia. The Congressional Research Service released a report in April 2010 that provides a concise overview of the funding and administration of the Older American's Act. For more information, visit:

U.S. Senate Special Committee on Aging 2010 Hearings
Congressional Research Service: "Older Americans Act: Funding"

3) Participants Report Title III Program Helps Them Remain in Their Homes

Mathematica Policy Research released a policy brief in which 85 percent of Title III participants reported that participating in these programs (home-delivered and congregate meals, case management, transportation, and homemaker and caregiver support) helped them to remain in their homes. For more information, visit:

Mathematica Policy Research: "Aging in Place: Do Older Americans Act Title III Services Reach Those Most Likely to Enter Nursing Homes?"

"The Older Americans Act is set to be re-authorized in 2011 and the Administration on Aging has a Web site for input on the reauthorization. Family Caregiver Alliance strongly encourages anybody who uses or administers Title III programs to provide feedback to the Administration on Aging through this Web site."

"...85 percent of Title III participants reported that participating in these programs (home-delivered and congregate meals, case management, transportation, and homemaker and caregiver support) helped them to remain in their homes."

4) Report Highlights Aging and Disability Resource Centers

The U.S. Administration on Aging (AoA) and the Centers for Medicare & Medicaid Services (CMS) have funded over \$110 million to states since 2003 to develop Aging and Disability Resource Centers (ADRCs) to assist people in accessing long-term services and support through a single entry point. A recent report from the National Health Policy Forum at George Washington University explains that ADRCs were originally created to assist people navigate long-term services and support. There are currently 325 ADRCs in 45 states. While AoA and CMS are specific about the expected functions of ADRCs, the authors explain that there is still considerable variation in the capabilities of ADRCs and how the functions are implemented. AoA and CMS developed six criteria to measure "fully functioning" ADRCs and AoA reports that as of September 2010, over 80 percent of states and territories implementing ADRCs have achieved more than half of the measurable outcomes, while almost 30 percent have achieved more than three quarters of the measurable outcomes. The Administration on Aging sponsors an ADRC technical assistance Exchange Web site with information and technical briefs on a variety of topics related for ADRC stakeholders, including cultural competence and assessing veterans.

For more information, visit:

[*National Health Policy Forum: "Aging and Disability Resource Centers \(ADRCs\): Federal and State Efforts to Guide Consumers Through the Long-Term Services and Supports Maze"*](#)
[*ADRC Technical Assistance Exchange Web site*](#)

5) Additional 12 States Receive Respite Grants

In 2009, the U.S. Administration on Aging funded 12 states to begin developing Lifespan Respite Care Programs and in 2010, an additional 12 states were granted funding. The funding is intended to assist states in supporting, expanding, and streamlining the delivery of planned and emergency respite services, train respite workers, and empower and train caregivers. For more information, visit:

[*Administration on Aging: Lifespan Respite Care Program*](#)
[*ARCH National Respite Network and Resource Center "State Lifespan Respite Programs"*](#)

6) Lifespan Respite Care Program Reauthorization Input Requested

The Administration on Aging is seeking input concerning the reauthorization of the Lifespan Respite Care Program (LRCP) that is expected to be reauthorized in 2011, effective for FY 2012. While legislation creating the program was passed in 2006 with appropriations of \$289 million for FY 2007 through FY 2011, Congress did not fund the program for FY 2007 or 2008, and funding for FY 2009 and FY 2010 was \$2.5 million each year. Input is due by March 31st, 2011, and the Lifespan Respite Task Force asks organizations and state agencies to comment on what they feel have been the effective components of the program. For more information, or to provide input, visit:

[*Administration on Aging*](#)
[*ARCH National Respite Network and Resource Center "Legislative Alerts"*](#)

7) GAO Report on the Lifespan Respite Care Program

The Government Accounting Office (GAO) released a report to Congress on the Lifespan Respite Care Program mandated by the Lifespan Respite Care Act of 2006. Since the program is relatively new, GAO could not carry out the cost benefit analysis required by the legislation, but they did prepare a descriptive summary of current state Lifespan Respite grantee activities. To conduct its required audit, GAO interviewed officials from AOA and reviewed related

documentation including grant applications, notice of awards, grantee work plans, and semi-annual progress reports. The ARCH program director was also interviewed to obtain background information on respite care and information about the National Resource Center on Lifespan Respite Care. The report includes a supportive statement from the Administration on Aging. For more information, visit:

GAO: "[Respite Care: Grants and Cooperative Agreements Awarded to Implement the Lifespan Respite Care Act. GAO-11-28R](#)"

Research Focused on Family Caregivers

"Without knowledge action is useless and knowledge without action is futile."
–Abu Bakr³⁴

Research in 2010 found that women were more likely to be caregivers in the U.S. and internationally, consistent with past research. Two new studies elaborated on the negative health effects of caregiving. One study suggested that family caregivers of people with dementia are more likely to develop dementia themselves. Another study found that caregiving places caregivers at an increased risk for stroke. On the bright side, spousal caregiving, especially hands on caregiving, was found to have positive psychological effects for spouses in a study published in *Psychology and Aging*. A number of studies addressed end-of-life care and provided empirical evidence on the benefits of palliative and hospice care and advanced planning for end-of-life care.

Family Caregivers in the United States

1) Unique Qualitative *and* Quantitative Data on Caregivers

The Families and Work Institute released a report that analyzes data on caregiving based on the ongoing National Study of the Changing Workforce. The report includes both quantitative data from a random sample in 2008 of 3,502 workers in the U.S. as well as qualitative interviews with 140 caregivers. The authors find that 42 percent of employed Americans have provided elder care ("special attention or care for a relative or in-law 65-years-old or older helping with things that were difficult or impossible for them to do themselves") in the past five years. Similar to past research, this study also finds that women are more likely to provide family care on a regular basis and spend more time than men providing care (9.1 hours on average per week for women, 6.4 hours for men).

"42 percent of employed Americans have provided elder care ("special attention or care for a relative or in-law 65-years-old or older helping with things that were difficult or impossible for them to do themselves") in the past five years."

Caregiving also creates financial challenges. Of the 38 percent of respondents who report taking time off or working fewer hours, 48 percent report losing income during their caregiving leave. In addition, 48 percent reported that they and/or their spouse helped cover the cost of care for their elder, with 27 percent perceiving this as somewhat of a burden, and 14 percent perceiving this as a great burden. In terms of caregiver health, 44 percent of current and former family caregivers report that caregiving has had a negative impact on the way they take care of themselves. The report includes individual responses from the qualitative interviews. One theme highlighted is that of caregivers having a negative view of the aging process: "An alarming theme that emerged from our interviews is that family caregivers

³⁴ Stockholm International Water Institute. Retrieved from: <http://www.siwi.org/knowledge>

overwhelmingly seem to view aging and receiving elder care as profoundly negative, depressing processes to be avoided if at all possible." For more information, visit: [Families and Work Institute: "The Elder Care Study: Everyday Realities and Wishes for Change"](#)

2) Differences in how Siblings Serve as Caregivers

A report released in August 2010 examined differences in how siblings provide care for their parents. Using a 50-year longitudinal study of 10,317 men and women who graduated from Wisconsin high schools in 1957, the report analyzed whether parents received caregiving assistance and if so, which children provided the assistance. The odds of one child helping the parents (as compared to no children helping) increased by 30 percent when one of the offspring was a sister. Parents with two sons (but no daughters) were least likely to receive help. In addition, married men were significantly more likely to assist their parents. For more information, visit: [California Center for Population Research: "Providing for Older Parents: Is It a Family Affair?"](#)

3) Significant and Unique Challenges for Veteran Caregivers

The National Alliance for Caregiving released a report in November detailing findings from their survey of 462 self-identified family caregivers who provide care to a veteran whose injury, illness, or condition is related to military service. The authors also conducted six focus groups and conducted 45 in-depth telephone interviews. The report compares the results of the survey to past caregiver research and finds that caregivers of veterans face unique caregiving burdens. For example, while 15 percent of caregivers report that they have been giving care for 10 years or more, 30 percent of veteran caregivers reported providing care for 10 years or more. Mental illness was the most prevalent illness reported (70 percent), followed by post traumatic stress disorder, which affected 60 percent of veteran care recipients. While 57 percent of caregivers nationally reported "having a choice" in taking on their caregiver role, only 29 percent of veteran caregivers felt that they had a choice. In this study, 96 percent of veteran caregivers were women, as compared to only 65 percent of caregivers nationally. For more information, visit:

[National Alliance for Caregiving: "Caregivers of Veterans – Serving on the Homefront"](#)

[National Public Radio "Study Spotlights Challenges Faced By Caregivers Of Veterans"](#)

4) Almost Two Million New Yorkers Are Caregivers

A 2010 report used data from the 2008 Behavioral Risk Factor Surveillance System (BRFSS) survey to estimate that there are 513,023 caregivers in upstate New York who provide an average of 11 hours of care per week. If the 1.4 million caregivers in downstate New York are included, the total number of caregivers in New York State is 1.9 million caregivers. The analysis was conducted by Excellus Blue Cross Blue Shield and found that the majority of caregivers are women (61 percent) and the majority of care recipients (61 percent) are aged 65 and older, although 35 percent are in the 18 to 64 age group. Almost one-third of respondents report that caregiver obligations affected their employment by either forcing them to take time off or reduce their work schedules while 11 percent reported retiring or leaving work because of caregiving responsibilities. The Florida Office on Disability and Health at the University of Florida has conducted analysis on data from several other states that have used the BRFSS survey (and accompanying caregiver modules) to better understand the demographics and numbers of caregivers in their state. For more information, visit:

Excellus Blue Cross Blue Shield: "Informal Caregiving in Upstate New York"
The Florida Office on Disability and Health at the University of Florida

5) Stress Variance in Family Caregivers

A May 2010 report surveyed family caregivers of persons with dementia (Alzheimer's or other) to compare mental health status of caregivers. Researchers found that personality factors explained over 20 percent of the variance in caregiver mental health status and depression. The authors conclude by suggesting that measures of personality factors, self-efficacy, mental health status, and distress response could be used for assessing caregivers and providing a multicomponent intervention program. For more information, visit: [American Journal of Alzheimer's Disease and Other Dementias: "Evaluation of an Assessment Battery for Estimating Dementia Caregiver Needs for Health and Social Care Services"](#)

6) Caregiver Stress Linked to Risk of Stroke

An article in the February 2010 issue of the journal *Stroke* (Volume 41, Issue 2) revealed that high caregiving strain was associated with a 23 percent higher estimated stroke risk, and that this association was stronger in men, particularly African American men with high caregiving strain. The researchers studied adults providing in-home care to a disabled spouse in order to learn the association of caregiving strain with stroke and coronary heart disease risk across race and sex. The study did not find an increased risk of heart disease linked to caregiver strain. For more information, visit: [Stroke: "Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers"](#)

7) Positive Effects of Spousal Caregiving

An article published in *Psychology and Aging* (Volume 25, Number 1), "Does a Helping Hand Mean a Heavy Heart?" examines the contexts in which providing care to an elderly spouse may result in positive outcomes. Psychologist Michael Poulin and colleagues found that spousal caregivers experience more positive emotions and fewer negative emotions when they engage in hands-on care, such as feeding and bathing, for their spouse. Spousal caregivers tend to experience more negative emotions when the care they provide is more passive, such as looking after a spouse to make sure nothing goes wrong or that he or she doesn't wander. For more information, visit: [Psychology and Aging "Does a Helping Hand Mean a Heavy Heart?"](#)

8) Caregiver Interventions Lack Cultural Tailoring

The August issue of the *American Journal of Alzheimer's Disease and Other Dementias* (Vol 25, Number 5) features a literature review focused on caregiver interventions and ethnic differences in family caregivers' experiences from 1980 to 2009. The authors explain that while there are a number of ethnic differences in caregiving, of the 47 intervention articles reviewed, only 18 reported outcomes by caregiver ethnicity. In addition, while 11 reported cultural tailoring, 8 were from a single initiative. Cultural tailoring addressed familism, language, literacy, protecting elders and logistical barriers. The authors conclude that more research is needed to systematically evaluate the benefits of cultural tailoring in caregiver interventions. To read "Developing Culturally Sensitive Dementia Caregiver Interventions: Are We There Yet?" by Dr. AM Napoles and colleagues, visit: [American Journal of Alzheimer's Disease and Other Dementias: "Developing Culturally Sensitive Dementia Caregiver Interventions: Are We There Yet?"](#)

Family Caregivers Outside of the U.S.

1) International Perspective of Caregiving Patterns

A Working Paper from CESifo in Germany assessed the relationship between family structure and the geographic proximity between adult children and their parents. The authors also examine whether differences in family structure affect the amount of informal care adult children provide to their elderly parents. Lastly, they looked for cross-country differences in family location and caregiving patterns. The results provide new insights into how family-related and institutional factors how adult children spend time with elderly parents. For more information, visit:

[*Institute for the Study of Labor: "Family Location and Caregiving Patterns from an International Perspective"*](#)

2) UN Paper Examines Caregiving from Macro and Micro Perspectives

The United Nations Economic and Social Commission for Asia and the Pacific (UNESCAP) published a paper on December 31, 2009 which examines the provision of care for older people at macro (national) and micro (individual or family) levels. The authors argue that these different levels are not mutually exclusive. Governments must be aware of the reality for families and their needs when crafting long-term care and caregiving policies, while individuals must also be aware of the programs and services available to them. This paper is part of the Gender and Development Discussion Series. For more information, visit:

[*United Nations Economic and Social Commission for Asia and the Pacific: "In the Care of the State and the Family: Understanding Care of the Elderly through Macro and Micro Perspectives"*](#)

3) Employment and Caregiving for Women in Europe

The authors use an economic model to study the prevalence of informal caregiving by adult women in Northern, Central, and Southern European countries. The authors begin their report by explaining that Northern European countries are considered to have generous long-term care programs while Southern countries provide only basic benefits for low-income elders. The authors also explain that one theory suggests that higher education levels and stronger labor force attachment may translate to fewer women in Northern countries serving as caregivers because of the higher opportunity costs. The authors find that in Southern countries parent health does have an impact on the daughter's probability of daily care-giving and of their probability of working, and even more significant impacts are found for combinations of low-education working daughters "close to the margin of non-participation, or daughters whose parents suffer from dementia." For more information, visit: [*Centro de Estudios Monetarios Y Financieros: "Caregiving to Elderly Parents and Employment Status of European Mature Women"*](#)

4) Informal and Formal Caregivers in the European Union

Dr. Judy Triantaffillou and colleagues examine the blurring line between informal and formal caregivers in the European Union (EU) in a report. The authors explain that informal caregivers provide most of the caregiving to older people in the EU and that this financial contribution is estimated to cover 50 to 90 percent of the overall costs of long term care. The authors provide a detailed comparison of how countries provide long term care throughout the EU and conclude that policymakers must recognize and support both formal and informal caregivers as they implement comprehensive solutions for long term care. For more information, visit:

[*European Commission under the Seventh Framework Programme: "Informal Care in the Long-Term Care System"*](#)

5) Report Estimates 700,000 Young Carers in United Kingdom

An article in *Medical News Today* highlighted a BBC report that found there are as many as 700,000 young carers working in the United Kingdom. Young carers were defined in the study as persons under age 18 whose lives are impacted by caring for someone who has an illness, a disability or issues with drugs or alcohol. The British Medical Association (BMA) Chairman Dr. Paul Darragh said, "The BMA has repeatedly highlighted the needs of young carers in Northern Ireland and called for huge reliance on informal carers to be addressed." The article cites research suggesting that there are 8,352 young carers in Northern Ireland and 712 of these carers provide over 50 hours of care per week. For more information, visit:

[*Medical News Today: "Don't Overlook Northern Ireland's Young Carers"*](#)
[*BBC News: "Cameron warns on child carer cuts"*](#)

6) Five Most Common Challenges Faced by Caregivers

The August edition of *British Medical Journal* features a qualitative study of the various challenges faced by caregivers. Through one-on-one interviews and focus groups, the authors identify five decision making areas that are consistently challenging for caregivers: accessing dementia related services, care homes, legal/financial matters, non-dementia related healthcare, and making plans for the care recipient if the caregiver becomes too ill to care for them. Caregivers explained that decision-making was often hampered by active resistance from the care receiver, legal authority is often insufficient and support from professionals was important for navigating the many hurdles in caregiving. For more information, visit:

[*British Medical Journal: "Making decisions for people with dementia who lack capacity: qualitative study of family carers in UK"*](#)

"...five decision making areas that are consistently challenging for caregivers: accessing dementia related services, care homes, legal/financial matters, non-dementia related healthcare, and making plans for the care recipient if the caregiver becomes too ill to care for them."

7) Consequences of Long-Distance Caregiving in Canada

A report from Statistics Canada focuses on the consequences of long-distance caregiving for adult children who are caregivers for a parent or parent-in-law. The study reveals that just over one in five caregivers lives more than an hour away from the assisted parent. Seventy percent of the caregivers had employment income and caregivers who lived further from the care recipient were more likely to miss work and were at increased risk for extra expenses compared to those who lived closer. Among long-distance caregivers, women were more likely than men to take time off from work. For more information, visit:

[*Statistics Canada: "Caring for a Parent Who Lives Far Way: The Consequences"*](#)

8) Older Adults' Access to Community Supports Information in Canada

A national survey of 1,152 adults aged 50 years and older in Canada provides insight into how older adults access information about community services. Researchers found that participants were most likely to use indirect routes to get information, including doctors and doctors' offices, informal sources (family, friends, neighbors), and the Internet. Participants' level of awareness also depended on the type of service; for example, participants were most likely to know about transportation, home support and dementia services. To read "Where Would You Turn for Help? Older Adults' Awareness of Community Support Services" (SEDAP Research Paper No. 272) by Dr. Margaret Denton and colleagues, visit:

[*Social and Economic Dimensions of an Aging Population*](#)

9) Report on Supporting Family Caregivers in New Zealand

The National Health Committee in New Zealand issued a report in January 2010 which makes recommendations to the Minister of Health about how to better support and provide services to informal caregivers. The report's recommendations are grouped into the following sections: reducing fragmentation in the care system; achieving national consistency and local flexibility of services; raising awareness; improving workforce capability; and preparing for the future. For more information, visit:

[*National Health Committee in New Zealand: "How Should We Care for the Carers: Now and Into the Future?"*](#)

Healthcare Support for Family Caregivers

Beyond juggling the day-to-day responsibilities of providing hands-on care, most family caregivers also have to navigate their loved ones through the healthcare system. Some of the most common challenges include learning about new condition(s) or disease(s), managing medications, communicating between various healthcare providers, submitting insurance claims, and making decisions about care settings and end-of-life care. FCA supports changes that empower patients and identifies and supports their caregivers, increases and improves communication, simplifies bureaucracy, and reduces the negative health impacts of caregiving on the family caregiver.

1) NASW Releases Standards for Social Work Practice with Family Caregivers

The National Association of Social Workers (NASW) announced the release of the NASW Standards for Social Work Practice with Family Caregivers of Older Adults. According to the authors, the standards are designed to enhance social workers' awareness of the skills, knowledge, values, methods, and sensitivity needed to work effectively with family caregivers. The standards were developed as part of an initiative with the AARP Foundation, the U.S. Administration on Aging, Family Caregiver Alliance, and the National Association of Social Workers, with funding support from the John A. Hartford Foundation. For more information, visit: [*National Association of Social Workers: "NASW Standards for Social Work Practice with Family Caregivers of Older Adults"*](#)

2) Communicating with Caregivers Position Paper by American College of Physicians

An article about the American College of Physicians position paper on how doctors can communicate with and support family caregivers was published in the January 2010 issue (Volume 25, Number 3) of the *Journal of General Internal Medicine*. In a related article in the *New York Times*, Dr. Pauline Chen discussed the need for physicians to acknowledge and support family caregivers who are active participants in providing patient care. Dr. Chen pointed out that it is uncommon for doctors to recognize the role of family caregivers because it is rarely part of their training and they are often not compensated for the time spent with caregivers. For more information, visit:

[New York Times: "Offering Care for the Caregiver"](#)

[American College of Physicians Position Paper: "Family Caregivers, Patients, and Physicians: Ethical Guidance to Optimize Relationships"](#)

3) Health and Human Services Revises Rule for Hospital Visiting Procedures

The Department of Health and Human Services (HHS) announced a final rule mandating that hospitals have written policies and procedures explaining to all patients their right to choose who may visit them during their inpatient stay as well as their right to withdraw consent for visitation at any time. The rules mean that patients will have the right to choose their own visitors during a hospital stay, including a visitor who is a same-sex domestic partner. The rules update the Conditions of Participation that all Medicare and Medicaid-participating hospitals and critical access hospitals must meet. Hospitals are also required to explain in their written policies the circumstances under which the hospital may restrict patient access to visitors based on reasonable clinical needs. For more information, visit: [Department of Health and Human Services: "Medicare finalizes new rules to require equal visitation rights for all hospital patients"](#)

4) New Guides Assist Hospital Staff and Caregivers

Next Step in Care released two helpful guides for caregivers. The first guide, "Reducing the Stress of Hospitalization for Patients with Dementia and Their Family Caregivers" introduces the reader to the topic from the perspective of a patient with Dementia who is in the Emergency Room. The guide gives practical advice for hospital staff to assist patients and their caregivers. The second guide, "Rehab to Home: Discharge Guide" is available in English, Spanish, Chinese and Russian and is written for family caregivers. The guide provides information about planning for a discharge, including equipment, household adaptations, medication, and how to appeal a discharge plan if a caregiver disagrees with the decision or feels it is unsafe. For more information, visit:

[Next Step in Care: "Reducing the Stress of Hospitalization for Patients with Dementia..."](#)

[Next Step in Care: "Rehab to Home: Discharge Guide"](#)

5) Texas: Insurance Commissioner Forbids Insurer Interpretation of Provisions

On December 6, 2010, the Insurance Commissioner of Texas, Mike Greeslin, formally adopted rules that remove insurers' blanket authority to interpret what their policies cover in Texas. The *Dallas Morning News* highlighted the changes and explained that prior to these rules being implemented, health and disability plans often included discretionary clauses that allowed insurers the right to interpret their own policies in deciding what benefits were required to be paid. In announcing the need for the rule, the Commissioner cited an insurance policy that stated it had "complete discretionary authority" to review all denied claims

to determine whether or not policyholders should have received benefits they were seeking. In addition to day-to-day caregiving issues, caregivers are often forced to work with insurance companies when insurance claims are delayed or denied. As a result of this new rule, consumers will now have the ability to challenge denial of benefits if they consider them unfair, either by contacting state regulators or filing a lawsuit against the company. Both options were described as nearly impossible previously because of the discretionary clauses. Texas joins 22 other states that have enacted bans on discretionary clauses. For more information, visit:

[*Dallas Morning News: "Texas' insurance commissioner forbids insurers' provisions that allowed them to interpret policies"*](#)

6) Campaign for Better Care Launched and Releases Study on Care Coordination

The Campaign for Better Care officially launched on April 8, 2010, and is a growing movement of patients, caregivers, advocates and concerned citizens working to ensure the promise of health reform. Run by the National Partnership for Women & Families, Community Catalyst and the National Health Law Program, this multi-year initiative focuses on improving healthcare quality, coordination and communication for older patients with multiple health problems and their family caregivers. One of the Campaign's key goals is to build a consumer movement of and for older adults with multiple chronic conditions who are counting on health reform to provide the comprehensive, coordinated, patient-centered care they need. For more information, visit: [*Campaign for Better Care*](#)

A survey conducted by The Campaign for Better Care reveals that "most older adults, and particularly those with multiple chronic conditions, have experienced poor care coordination and a lack of information because their doctors aren't talking to each other or to them." The survey of adults age 50 and older finds that three in four respondents (74 percent) have wished that their doctors talked and shared information with each other. This issue impacts family caregivers, who are often the advocate and act as the care coordinator for adults with dementia or multiple chronic conditions. For more information, visit: [*Campaign for Better Care: "Health Survey Shows Older Adults Suffering Due to Poor Care Coordination, Inadequate Communication Among Doctors"*](#)

7) Guide on Sexuality and Dementia in Residential Care Facilities

Alzheimer's Australia released a guide for use by people living with dementia, family members, caregivers, and health professionals about sexuality and dementia within the context of residential care facilities. The author of the guide explains that it will not provide "easy solutions," however, the guide does provide a context for discussions about sexuality, consent, privacy, risk management, and developing appropriate policies. This guide is part of a longer series on working with patients with dementia. For more information, visit: [*Alzheimer's Australia: "Understanding Dementia Care and Sexuality in Residential Facilities"*](#)

8) Half of Elderly Participants Taking Inappropriate Medications in Review

A study in the September issue (Volume 3, Number 8) of *Irish Medical Journal* features a study in which 50 participants participated in a brief, ten minute medication review. The mean age of participants was 73, and 88 percent of patients had some changes made to their medication after the review. Inappropriate medications were detected and changed in 54 percent of the participants and 70 percent of participants required cessation of at least one medication. Patients and their caregivers often have to keep track of a number of medications and this study highlights the importance of speaking regularly with a doctor about all prescription and over-the-counter medications. Ninety-six percent of the participants reported that they would like a repeat review.

To read "Take Ten Minutes: A Dedicated Ten Minute Medication Review Reduces Polypharmacy in the Elderly" by EK Walsh and colleagues, visit: [*Irish Medical Journal: "Take Ten Minutes: A Dedicated Ten Minute Medication Review Reduces Polypharmacy in the Elderly"*](#)

"Inappropriate medications were detected and changed in 54 percent of the participants and 70 percent of participants required cessation of at least one medication."

9) Massachusetts: Campaign to Reduce the Overuse of Antipsychotic Medications

On November 18, 2010, state regulators and the Massachusetts nursing home industry launched a campaign to reduce the overuse of the antipsychotic medications especially prescribed to dementia residents who display difficult behaviors. The *Boston Globe* reports that 22 percent of Massachusetts nursing home residents in 2009 who were given antipsychotic medications did not have a diagnosis for which the medications would be prescribed - the 12th highest percent in the nation. A report from this task force suggests that the overuse of antipsychotic medications is attributed to nursing home understaffing, a lack of training for front-line care-workers, and a lack of knowledge of available alternative approaches such as music or massage. Alice Bonner, the Director of the Bureau of Health Care Safety and Quality in the Department of Public Health said that the task force identified other low-cost approaches including a more careful screening of newly admitted patients by asking family members about the patient's personality or behavior before the onset of illness. Bonner explained that patients benefit from nursing homes giving their workers consistent schedules because it means that patients are interacting with the same workers. Bonner said, "that helps reduce difficult behaviors with patients with dementia. Because staff knows them better, they can pick up on early signs of trouble and prevent a catastrophic event, so they can intervene early." The campaign will also utilize the work of Dr. Susan Wehry, a Geriatric Psychiatrist affiliated with the University of Vermont, at the College of Medicine. Wehry recently finished a nine-month study in four Vermont nursing homes that taught alternative approaches. Based on her research, making training mandatory for staff reduces overuse of antipsychotic medications. For more information, visit:

[*The Boston Globe: "Mass. aims to cut drug overuse for dementia"*](#)

Balancing Caregiving and Employment

The challenges of balancing the role of caregiver and the role of employee are well-known to almost half of Americans, according to some of the most recent research released in 2010. In his analysis of the CLASS Act, Professor Richard Kaplan explained the plight faced by family caregivers who provide the bulk of long-term care “without charge.”

Without charge, however, is not the same as without cost. Many family caregivers who provide this care often curtail their hours at a compensated position, while others decline travel and promotion opportunities to maintain their ability to provide the care that their relatives require. Still others shift to part-time employment or terminate their employment completely, with often dire economic consequences to their future retirement prospects, because Social Security benefits are based on the earnings that they receive over a 35-year work life. Similarly, without compensated employment, family caregivers have limited access to 401(k) retirement savings plans or self-funded Individual Retirement Accounts (IRAs). To offset this sacrifice, some care recipients pay their caregivers via “Family Caregiver Agreements,” but such arrangements are more the exception than the norm.³⁵

“Without charge, however, is not the same as without cost. Many family caregivers who provide this care often curtail their hours at a compensated position, while others decline travel and promotion opportunities to maintain their ability to provide the care that their relatives require.”

- Professor Richard Kaplan

1) Eighty-six Percent of Americans Support Paid Sick Days According to Poll

On June 21, 2010, the Public Welfare Foundation released a poll that finds 86 percent of respondents favor a plan that guarantees workers seven paid sick days a year. Nearly one-fourth (23 percent) of respondents reported having lost a job or been threatened with job loss for taking time off from work to care for a sick child or family member or to cope with their own illness, and 16 percent reported having actually lost a job. A bill introduced (but not enacted) in the 111th Congress, *the Healthy Families Act*, would have required most employers to provide workers with paid sick days. For more information, visit: [Public Welfare Foundation: "Paid Sick Days: Attitudes and Experiences"](#)

2) Discrimination Alleged against Employed Caregivers

NPR aired a story in June 2010 on caregiver discrimination in the workplace, reporting that there is “no federal law that bans workplace discrimination against parents or people who care for elderly or disabled family members.” Regardless, the number of lawsuits by employees who allege that they were discriminated against because of their caregiving responsibilities has grown in the past decade. In part as a result, the Equal Employment Opportunity Commission (EEOC) has issued guidance on how to combat caregiver discrimination and how employers can treat their employees fairly and avoid such lawsuits. For more information, visit: [NPR: "More Workers Alleging Bias Against Caregivers"](#)

³⁵ Kaplan, Richard L., (2010, July-August). Financing Long-Term Care After Health Care Reform. *Journal of Retirement Planning*, p. 9. Illinois Program in Law, Behavior and Social Science Paper No. LE10-001. Retrieved from <http://ssrn.com/abstract=1692288>

3) Fact Sheet Highlights Challenges Faced by Employed Family Caregivers

The National Partnership for Women and Families released a fact sheet on employed family caregivers and the challenges they face in the workplace. The fact sheet highlights the conflicts caregivers face when they are forced to choose between caring for a loved-one or keeping their job. According to the report, nearly six in ten caregivers are employed and more than seven in ten were employed at some point during their caregiving role. A continuing challenge for the working family caregiver is that the workplace hasn't adapted to meet the needs of caregiving. Serving as a family caregiver while working can mean risking discipline, loss of pay, promotion, or even job loss. In many cases, caregivers are forced to decide between keeping their job or being a caregiver. In 2009 there were 66 million Americans who served as unpaid caregivers. For more information, visit: [National Partnership for Women and Families: "Building Better Workplace for Family Caregivers"](#)

4) New Web site Addresses Workplace Flexibility

The Sloan Center on Aging and Work at Boston College launched a Web site this year focused on workplace flexibility. Workplace flexibility (or lack thereof) is an issue faced by many family caregivers and this Web site provides information for employees and employers, including case studies, types of flexibility, challenges in implementing flexibility in the workplace, and the benefits of flexibility for employees and employers. For more information, visit: [The Sloan Center on Aging and Work at Boston College](#)

5) Impact of Caregiving and Employment on the Caregiver's Well-Being

A study in *Health Management* (Vol. 2, Issue 1) used data from a survey of over 240,000 Americans and found that respondents who were caregivers and who were employed reported higher levels of well-being than respondents who were caregivers but who were not employed. In addition, employees who were not caregivers reported higher levels of well-being than employees who were caregivers. For more information, visit: [Health Management: "Estimating the Impact of Caregiving and Employment on Well-Being"](#)

6) Working Caregivers and Employer Healthcare Costs

The MetLife Mature Market Institute with the National Alliance for Caregiving in conjunction with the University of Pittsburgh Institute of Aging released a report in February 2010 focused on caregiving and employer healthcare costs. The report reveals that working caregivers, who tend to experience more health problems than non-caregivers, cost employers an estimated average of an additional 8 percent in healthcare expenses per year, or \$13.4 billion annually. The report also found that younger caregivers (ages 18 to 39) cost their employers 11 percent more for healthcare than non-caregivers, while male caregivers cost an additional 18 percent. The authors suggest employers provide integrated wellness and eldercare programs for employees. For more information, visit: [MetLife Mature Market Institute: "MetLife Study of Working Caregivers and Employer Health Care Costs"](#)

7) Survey: "Baby Boomers' Caregiving Duties Impact Jobs and Health"

A research study by the Hartford Financial Services Group, Inc. and ComPsych Corporation reveals that "the demands of balancing a full-time job and caring for an injured or ill family member is a major source of stress for many Baby Boomers and is impacting their productivity and their health." The study, which surveyed ComPsych employees who had accessed the company's Employee Assistance Program, found that "younger Baby Boomers, ages 45 to 54, are carrying the largest burden of family care responsibilities, with more than half saying they've taken time off from work due to their caregiving responsibilities." The article offers recommendations to employers on how they can help relieve the pressure felt by working caregivers. For more information, visit: [The Hartford: "Research By The Hartford And ComPsych Finds Baby Boomers' Caregiving Duties Impact Jobs And Health"](#)

Caregiving and Dementia

1) Collaborative Effort to Share Alzheimer's Research Pays Dividends

In August, the *New York Times* profiled a unique, joint effort by Alzheimer's researchers to share data and research in an effort to find the biological markers that show the progression of Alzheimer's in the brain. The joint research study, the Alzheimer's Disease Neuroimaging Initiative (ADNI), began in 2003 and represents a new way of conducting research in which all of the data is publicly shared. A number of governmental, business, and nonprofits provided funding and partnered in the initiative and this model is now being used for a similar Parkinson's study. For more information, visit: [The New York Times: "Sharing of Data Leads to Progress on Alzheimer's"](#)

2) Colombian Clan with Dementia Mutation Part of Efforts to Cure Alzheimer's

A November *New York Times* article provided an update on Alzheimer's research and focused on a clan in Colombia in which members tend to inherit a genetic mutation that guarantees they will develop dementia, generally in their forties. A research team consisting of American and Colombian scientists plans to test treatments on Colombians in their late thirties and early forties to see if dementia can be either prevented or significantly delayed. Testing for the project is expected to begin in 2011 or early 2012. For more information, visit: [New York Times: "For Edge on Alzheimer's, Testing Early Treatments"](#)

3) Driving Risk for Patients with Dementia

The authors of a study featured in the April issue of *Neurology* (Volume 74, Issue 16) reviewed 422 articles related to dementia and driving to update the 2000 American Academy of Neurology practice parameters on driving and dementia. The authors cite research that while patients with dementia are higher risk drivers, as many as 76 percent of patients with mild dementia are able to pass an on-road driving test and can safely drive. The authors conclude that six characteristics are helpful for identifying patients at increased risk for unsafe driving, while two are considered not useful. Family Caregiver Alliance's Web site features a fact-sheet on dementia and driving that provides suggestions for caregivers and the American Medical Association produced a free guide for doctors that lists laws in each state related to driving and dementia. For more information, visit: [Neurology: "Practice Parameter update: Evaluation and management of driving risk in dementia"](#)
[Family Caregiver Alliance "Dementia and Driving Fact Sheet"](#)
[AMA Physician's Guide to Assessing and Counseling Older Drivers](#)

4) Spirituality for Residents with Dementia in Long-Term Care Facilities

The October issue of *Annals of Long-Term Care: Clinical Care and Aging* (Volume 18, Issue 10) includes a literature review of articles addressing spirituality for residents with dementia in long-term care facilities. After all screenings and reviews, 13 articles were included and the authors identify three major themes present in all 13 articles: spiritual needs, methods of assessment, and clinical guidelines. Seven articles discuss clinical guidelines and include suggestions to assist staff to provide spiritual care. Eight articles discuss the spiritual needs of residents, and the authors identify three sub-themes, including individuals maintaining a sense of meaning and purpose; the need to preserve meaningful connections with others, and the need for residents to have a relationship with God. Five articles in the review discuss methods to assess the spiritual needs of residents, including MacKinlay's 2-level method of assessment. However, the authors explain that a check-box scale may not be a valid spirituality needs assessment and staff may need to also use observations and intuition to meet residents' spiritual needs. For more information, visit:

[*Annals of Long-Term Care: Clinical Care and Aging: "A Systematic Review of Spirituality and Dementia in LTC"*](#)

5) Dementia Spousal Caregivers More Likely to Get Dementia

An article in the May 2010 issue of the *Journal of the American Geriatrics Society* (Volume 58, Issue 5) reveals that spousal caregivers of people with dementia are more likely than noncaregivers to get dementia themselves. The study followed 1,221 married couples aged 65 and older in Utah. The authors conclude that "the chronic and often severe stress associated with dementia caregiving may exert substantial risk for the development of dementia in spouse caregivers." The journal also includes an editorial by Peter P. Vitaliano, Ph.D. about the "ironic tragedy" of the study's findings. For more information, visit:

[*Journal of the American Geriatrics Society: "Greater Risk of Dementia When Spouse Has Dementia? The Cache County Study"*](#)
[*CNN: "Can caring make you sick?"*](#)

6) Midlife Stress Lined to Increased Risks of Dementia

The May 2010 issue of *Brain* features a longitudinal study on the relationship between psychological stress in midlife and the development of dementia in late-life. A representative sample of females aged 38-60 years were examined in 1968-69, and re-examined in 1974-75, 1980-81, 1992-93 and 2000-03. During the 35-year follow-up, 161 females had developed dementia (105 Alzheimer's disease, 40 vascular dementia and 16 other dementias). The risk of dementia was about 65 percent greater for women who reported stress in midlife as compared to those who did not. For more information, visit:

[*Brain: "Midlife Psychological Stress and Risk of Dementia"*](#)

7) Link between Post-Traumatic Stress Disorder and Dementia

The September issue of the *Journal of the American Geriatrics Society* (Volume 58, Issue 9) features a study that found that Veterans with post-traumatic stress disorder (PTSD) were twice as likely to develop dementia compared to Veterans without PTSD. The study included 10,481 Veterans aged 65 or older and could have important implications for future Veteran care because of the number of Veterans who have served in Iraq and Afghanistan. In July, the Department of Veteran Affairs announced new rules intended to simplify the process for Veterans to claim service connection for PTSD that is also expected to reduce the amount of time for claims processing. A 2008 Rand Corporation Study interviewed 1,965 Veterans and servicemenbers of the conflicts in Iraq and Afghanistan and found that 14 percent screened positive for PTSD while 19 percent reported a probable Traumatic Brain Injury (TBI) during deployment. For more information, visit:

Journal of the American Geriatrics Society: "Greater Prevalence and Incidence of Dementia in Older Veterans with Posttraumatic Stress Disorder"

Rand Corporation: "Invisible Wounds of War: Psychological and Cognitive Injuries, Their Consequences, and Services to Assist Recovery"

8) Telephone Support Groups for Caregivers of Veterans with Dementia

The September issue of the *Gerontologist* (Volume 50, Issue 5) features a study that evaluates how a caregiver telephone support and education group could reduce costs of care for Veterans with Dementia. The year-long study included 158 spousal caregivers, half of whom received monthly, 1-hour sessions of telephone education and support on care recipient healthcare. At six months, the patient costs for the caregivers receiving the telephone support/education were \$2,768 less than the group that did not receive telephone support/education. However, these costs were not maintained at the one year mark. Each expense was assessed separately and only the nursing home costs reached statistical significance with a savings of \$1,057. The authors suggest that future studies could measure if phone support/education groups also have outcomes for the caregiver. For more information, visit:

The Gerontologist: "The Effects of Telephone Support Groups on Costs of Care for Veterans With Dementia"

Statistics about Alzheimer's Disease

1) Report Details Costs of Alzheimer's Crisis

The Alzheimer's Association released a report in May 2010 titled "Changing the Trajectory of Alzheimer's Disease: A National Imperative." The report examines the current projections and costs associated with the Alzheimer crisis, as well as what Medicare and Medicaid savings are possible if disease modifying treatments were available. It reveals that, from 2010 to 2050, the total costs of care for Americans age 65 and older with Alzheimer's disease will increase five-fold, from \$172 billion to \$1.08 trillion per year, including out-of-pocket costs to caregiving families. For more information, visit:

Alzheimer's Association: "Changing the Trajectory of Alzheimer's Disease: A National Imperative."

2) 2010 Alzheimer's Disease Facts and Figures

The Alzheimer's Association released the 2010 Alzheimer's Disease Facts and Figures that provides U.S. data on Alzheimer's disease and other dementias, including prevalence, mortality, lifetime risk, caregiving information, and use and costs of care and services. This report reveals that, in 2009, there were nearly 11 million informal caregivers providing 12.5 billion hours of care valued at \$144 billion to people with Alzheimer's disease and other dementias. For more information, visit:

[*Alzheimer's Association: "2010 Alzheimer's Disease Facts and Figures"*](#)

3) The Cost of Dementia Care

According to the newly released *World Alzheimer Report 2010: The Global Economic Impact of Dementia* if dementia care were a company, it would be the world's largest company by annual revenue, exceeding Wal-Mart (\$414 billion) or Exxon (\$311 billion). The total worldwide cost of dementia care in 2010 is \$604 billion. ADI, a non-profit based in London, is a federation of 73 national Alzheimer's organizations, including the U.S. Alzheimer's Association. For more information, visit:

[*Alzheimer's Disease International: "World Alzheimer Report 2010: The Global Economic Impact of Dementia"*](#)

4) Prevalence and Cost of Dementia in United Kingdom

A report by the Alzheimer's Research Trust (ART) at Oxford University revealed that the cost of caring for people with dementia in the United Kingdom is far higher than previously thought, and that dementia research receives far less funding than other prevalent diseases. *Dementia 2010* reports on the prevalence, economic cost and research funding of dementia compared with other diseases. Dementia costs the United Kingdom £23 billion (\$37 billion) a year, more than cancer and heart disease combined, and the number of people with dementia is expected to rise nearly 20 percent to over a million by 2025. For more information, visit:

[*Alzheimer's Research Trust: "Dementia 2010: The economic burden of dementia and associated research funding in the United Kingdom"*](#)

5) Alzheimer's Sufferers will Increase 282 percent by 2050 in Australia

An Access Economics study commissioned by Alzheimer's Australia revealed that the number of adults with dementia in Australia is currently at 257,000 and is expected to increase to 981,000 by 2050, a 282 percent increase. The report explains that that increase will be driven largely by population growth and ageing baby boomers. For more information, visit: [*Alzheimer's Australia: "Caring places: planning for aged care and dementia 2010-2050"*](#)

[*The Sydney Morning-Herald: "Alzheimers sufferers to quadruple"*](#)

6) Caregiving and Alzheimer's Disease in Canada

The Canadian Institute for Health Information recently released two reports focused on family caregivers in Canada. The authors use data gathered from Canada's Home Care Reporting System and an assessment instrument used for home care clients. In the first report, "Supporting Informal Caregivers- The Heart of Home Care," the authors analyze a sample of 131,000 home care clients age 65 and older. Caregiver distress (defined in the study as "the overall impact of physical, psychological, social and financial demands of caregiving") is correlated with the amount of time spent caregiving.

Clients who receive 21 or more hours of care per week are four times more likely to have a distressed caregiver than those who receive 10 hours or less per week (28 percent vs. 7 percent). The caregivers with the highest rates of distress care for home care clients who exhibit verbally and/or physically abusive behavior. For more information, visit:

[*Canadian Institute for Health Information: "Supporting Informal Caregivers- The Heart of Home Care"*](#)

In the second report, "Caring for Seniors With Alzheimer's Disease and Other Forms of Dementia," the authors discuss dementia, caregiving, and residential care vs. home care services. For higher-functioning seniors with dementia, those who are newly admitted to residential care are twice as likely to be unmarried, highlighting the role of spousal family caregivers. Nearly all of the home care clients with a dementia diagnosis (99 percent) receive support from at least one informal caregiver. The authors also find that the strongest predictor of a senior with dementia living in residential care instead of home care is the practice of wandering. The odds of being newly admitted to residential care are seven times higher for seniors who wander as compared to those who do not. For more information, visit:

[*Canadian Institute for Health Information: "Caring for Seniors With Alzheimer's Disease and Other Forms of Dementia"*](#)

7) Impact of Dementia on Canadian Society

The Alzheimer Society in Canada recently released *Rising Tide: The Impact of Dementia on Canadian Society*. This research, conducted by RiskAnalytica, reveals the health burden of Alzheimer's disease in Canada over the next thirty years, the economic consequences of dementia, and opportunities and recommendations for intervention. Specifically, the report finds that the number of hours of informal care provided to people with dementia in Canada will triple in the next thirty years, increasing from 231 million hours in 2008 to 756 million hours in 2038. For more information, visit:

[*Alzheimer Society: "Rising Tide: The Impact of Dementia on Canadian Society"*](#)

Palliative, Hospice, and End-of-Life Care Preferences

Family Caregivers and their loved ones are often faced with difficult decisions around healthcare, and one of the most difficult areas is end-of-life care. While the Affordable Care Act originally included Medicare reimbursement for doctors to discuss end-of-life preferences with their patients, this was removed because of political pressure created by the term "death panels." The Department of Health and Human Services briefly re-included these appointments as a reimbursable expense under Medicare, however, this provision was removed again at the beginning of January 2011. While conversations around end-of-life care are difficult, research also suggests that advanced planning reduces

"Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars."

– Dr. Atul Gawande

stress and anxiety for patients and also reduces depression for surviving relatives.³⁶

Hospice and palliative care were also the subject of several studies. One study found that patients with newly diagnosed metastatic lung cancer who received palliative care with standard cancer therapy experienced less depression, were less likely to receive aggressive end-of-life care and lived almost three months longer than participants who only received cancer treatment.³⁷ Under the Affordable Care Act, HHS is directed to create a three-year Medicare Hospice Concurrent Care Demonstration Program at not more than 15 sites that will allow patients to receive both hospice and curative care at the same time.³⁸

1) Palliative and Hospice Care from a Doctor and Patient's Perspective

Dr. Atul Gawande, a doctor, and healthcare policy expert, captured the difficult issues, decisions, and conversations that patients, doctors, and family caregivers face around end-of-life care in his August article in the *New Yorker* entitled "Letting Go."

People have concerns besides simply prolonging their lives. Surveys of patients with terminal illness find that their top priorities include, in addition to avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others. Our system of technological medical care has utterly failed to meet these needs, and the cost of this failure is measured in far more than dollars. The hard question we face, then, is not how we can afford this system's expense. It is how we can build a healthcare system that will actually help dying patients achieve what's most important to them at the end of their lives.

To read all of Dr. Gawande's article, visit the *New Yorker* Web site: "[Letting Go](#)"

2) New Law in New York Requires Doctors to Discuss Palliative Care

New York Governor David A. Paterson signed the New York Palliative Care Information Act which will change how doctors work with patients who have a terminal illness or condition. Under the new law, doctors will be required to offer information about prognosis and options for end-of-life care, hospice care, and possibilities for life-sustaining treatment. *New York Times*: "[Frank Talk About Care at Life's End](#)"

3) Palliative Care for Patients with Dementia

The November issue of the *Journal of the American Geriatrics Society* (Volume 58, Issue 11) includes an article based on a survey of 426 hospice and palliative care program directors about the provision and challenges of providing palliative care to patients with dementia. In the survey, 94 percent of hospice and 72 percent of palliative care directors report that they have recently cared for

³⁶ Detering, K.M., Hancock, A.D., Reade, M.C., & Silvester, W. (2010, March 23). The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*.340:c1345. Retrieved from <http://www.bmj.com/content/340/bmj.c1345.full>

³⁷ Brody, Jane. (2010, August 23). Frank Talk about Care at Life's End. *New York Times*. Retrieved from http://www.nytimes.com/2010/08/24/health/24brod.html?_r=2&emc=tnt&tntemail0=y

³⁸ Note: Under current law, Medicare beneficiaries can only receive hospice care if their doctor believes they have less than six months to live and the beneficiary agrees to forego any additional curative treatments. Patient Protection and Affordable Care Act, Public Law 111-148, (2010). Section 3140 "Medicare Hospice Concurrent Care Demonstration Program" (page 322). Retrieved from <http://democrats.senate.gov/reform/patient-protection-affordable-care-act-as-passed.pdf>

patients with dementia, as compared to a 1995 study that found only 21 percent of hospice programs had provided this type of care. The respondents report that the most common barriers to providing palliative care include a lack of awareness by family members and referring providers, the need for respite services, and reimbursement policies. The most commonly cited needs were family information, assistance with caregiver burden, and behavioral symptoms. Successful strategies included interdisciplinary teams, collaboration with community organizations, and alternatives to aggressive end-of-life care. The first author of the study, Dr. Alexia M. Torke, explains, "Although the general public and many physicians do not associate palliative or hospice care with dementia, dementia is a terminal disease and should be respected as such. Palliative care is needed throughout the illness and can provide those who are unable to communicate their needs with a better quality of life as well as lowering the stress the illness places on caregivers and the entire family." For more information, visit:

[*Journal of the American Geriatrics Society: "Palliative Care for Patients with Dementia: A National Survey"*](#)

[*EurekAlert Summary: "Palliative care for patients with dementia more available but still not adequate"*](#)

"In the survey, 94 percent of hospice and 72 percent of palliative care directors report that they have recently cared for patients with dementia, as compared to a 1995 study that found only 21 percent of hospice programs had provided this type of care."

4) Palliative Care Improves Quality of Life for Lung Cancer Patients in Study

A study in the *New England Journal of Medicine* (Vol. 363 Number 8) found several improvements in quality of life for patients who received palliative care with standard cancer treatment vs. patients who only received standard cancer treatment. Patients who received palliative care reported a higher quality of life, less depressive symptoms and lived almost three months longer on average, despite the fact that they were less likely to receive aggressive end-of-life treatment. For more information, visit:

[*New England Journal of Medicine: "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer"*](#)

5) Advanced Care Planning Improves Care, Reduces Stress and Depression

Research published on March 23, 2010 on *BMJ.com* reveals that advance care planning improves end of life care and reduces stress, anxiety and depression in surviving relatives. The study followed 309 patients age 80 and older in Australia, half of whom were given advance care planning from trained staff, to study whether the patients' end of life wishes were known and respected, as well as to evaluate family members' stress, anxiety and depression. For more information, visit:

[*BMJ.com "The impact of advance care planning on end of life care in elderly patients: randomised controlled trial"*](#)

6) Differences in End-Of-Life Care Preferences Being Followed

A report in the September issue of *Archives of Internal Medicine* (Volume 170, Number 17) focuses on end of life (EOL) care for 71 black and 261 white patients with advanced cancer. The authors attempt to discern why black patients tend to receive more life-prolonging care while white patients are more likely to receive comfort-directed care. While the black and white patients had similar rates of EOL discussions, the authors found several differences, including black patients being less aware of the terminal nature of their disease and white patients being more likely to have Do Not Resuscitate (DNR) orders in place and preferred symptom-directed care as compared to life-prolonging EOL care. However, black patients who had Do Not Resuscitate (DNR) orders were "no less likely than black patients without DNR orders to receive life-prolonging care." For more information, visit:

[*Archives of Internal Medicine: "Racial Disparities in the Outcomes of Communication on Medical Care Received Near Death"*](#)

7) Report Highlights Room for Improvement in Advanced Care Planning

The Older Women's League (OWL) released its 12th annual Mother's Day report, "*End-of-Life-Choices: Who Decides?*" that calls for a broad range of changes "to promote and protect autonomy and control in end-of-life decision making and ensure a dignified death for each of us." The report includes recommendations for legislators, public health agencies, nonprofit organizations, community advocates and healthcare providers. For more information, visit: [*Older Women's League: "End-of-Life-Choices: Who Decides?"*](#)

8) Report Finds Inconsistent Treatment Approaches for Life-Ending Cancer

A recent report by the Dartmouth Atlas of Health Care suggests that patients with life-ending cancers are receiving vastly different treatments based on the hospital where they are treated. Treatments ranged from chemotherapy and other life-prolonging efforts at some hospitals while other hospitals directed most of their patients to hospice care. The authors examine how care was provided to Medicare patients over age 65 with cancer that had poor prognoses, and found that over one-third of patients with poor prognoses spent their final days in hospitals and intensive care units. In at least 50 academic medical centers, less than half of patients with poor prognoses received hospice services. For more information, visit:

[*Dartmouth Atlas of Health Care: "Quality of End-of-Life Cancer Care for Medicare Beneficiaries"*](#)

[*Kaiser Health News: "Hospice or Hospital? Where You Die Depends On Where You Live"*](#)

U.S. and International Government Preparedness for the Approaching “Silver Tsunami”

Shifting demographics, a retiring work-force, low birth rates in some countries, under-funded retirements and rising healthcare costs have all contributed to what has been described as the approaching “Silver Tsunami.” Researchers have analyzed aspects of this approaching crisis as well as government responses (or lack thereof) in the several reports below.

1) Impending Caregiving Crisis

The Rosalynn Carter Institute for Caregiving (RCI) released a report in October 2010 that addresses the approaching “Silver Tsunami” of an aging demographic, longer life expectancies, chronic illnesses, and a burdened healthcare system. RCI calls for a “National Caregiving Initiative” to improve the support system for family caregivers. Recommendations include better data collection through the Behavioral Risk Factor Surveillance System (BRFSS); broad implementation of culturally competent caregiver assessments; and improvements to the tax code and Social Security system that would recognize caregiving through tax credits for family caregivers and credits for caregiving in the Social Security calculation of benefits. For more information, visit:

[*Rosalynn Carter Institute for Caregiving "Averting the Caregiving Crisis Why We Must Act Now"*](#)

2) International Global Aging Preparedness Index

Three recent stories focused on the oncoming silver tsunami of declining birth rates, an aging population, and underfunded retirement programs. The Center for Strategic and International Studies released an index that measures how well 20 countries are prepared to care for a growing aging population. In their accompanying report, the authors include a reform guide that analyzes the benefits of seven reform strategies, including reducing public pension benefits and increasing immigration. Australia is highlighted for its low-cost, means-tested "floor" of public old-age poverty protection combined with a large, fully-funded, mandatory pension system. The *New York Times* featured an Op-Ed by the authors about their index. A recent National Public Radio interview featured Ted Fishman, the author of the new book, "Shock of Gray" that highlights the fact that in 2030 more than 1 billion people in the world will be over the age of 50. For more information, visit:

[*Center for Strategic and International Studies: "The Global Aging Preparedness Index"*](#)

[*New York Times Op-Ed: "Here Come the Elderly"*](#)

[*National Public Radio: "Our Aging World Is In For A 'Shock Of Gray'"*](#)

3) Alberta Aging Population Policy Framework

The government of Alberta released its "Aging Population Policy Framework" on November 8, based on research completed in 2008 that consulted 100 stakeholder groups and conducted an online survey of 10,000 Albertans. The survey identifies eight strategic policy priorities to address the 650,000 Albertans who will be age 65 or older by 2020. The policy directions include raising awareness about the cost of retirement, providing career services for mature workers, and assisting employers with a "multi-generational workforce." Additional directions include supporting senior drivers and providing affordable transportation when driving is no longer feasible, increasing awareness/prevention of elder abuse, easing access to government services, and building "age friendly" communities. In response to criticism that the report

doesn't create new policies or programs, the Minister of Aging explained that the report provides a framework for future planning on how to address this growing population. For more information, visit:

[Government of Alberta: "Aging Population Policy Framework"](#)

[Edmonton Journal: "Alberta not ready for senior boom, critics say"](#)

4) Older Adults in California Need More to Survive

Recently released Census data found that 43.6 million Americans were living below the Federal Poverty Line (FPL) in 2009, which is \$22,050 for a family of four. While this figure represents over 14 percent of Americans living in poverty, a recent policy brief suggests a more accurate way to measure the cost of living. The alternative measure is called the Elder Index and is a county-specific benchmark about the cost of basic needs (food, housing, healthcare, and transportation). Using this index, the authors explain that older Californians need \$21,763 per year (on average) in order to meet basic living expenses, which is more than twice the amount of money (\$10,830) suggested by the FPL. This finding has important implications for seniors and their caregivers because many government programs use the FPL both for eligibility criteria and in decision-making about how to target services. The authors report that 60 percent of the Area Agencies on Aging in California have shifted to using the Elder Index in their strategic plans to keep older adults living in their homes independently. Legislation has also been introduced (AB 2114) to require California's Department of Aging to utilize the Elder Index. For more information, visit:

[UCLA Center for Health Policy Research: "Older Adults Need Twice the Federal Poverty Line to Make Ends Meet in California"](#)

Family Caregiving Experiences Addressed in the Media

Family caregivers and the challenges they face were profiled in multiple stories throughout 2010. FCA included the articles below because they articulate the most challenging issues faced by caregivers while also intertwining the relevant policy issues, including the increased health risks for family caregivers, support for employed caregivers, veteran healthcare, the "sandwich generation" of caregivers and advocacy efforts to improve support for family caregivers.

1) Article Highlights Silent Struggle of Being a Caregiver

An article by Jonathan Rauch in the April 2010 issue of *The Atlantic* describes his experience caring for his aging father and the stress and struggles associated with caregiving. Rauch makes the point that millions of Americans are silently dealing with the challenges of caregiving, and he argues that the issue needs to become a public one and that resources and services need to be more readily available. For more information, visit: [The Atlantic: "Letting Go of My Father"](#)

2) Writer Focuses on Wife's Experience as Caregiver to Husband

Katy Butler's June 2010 article in the *New York Times Magazine*, captured the experience of the author's mother as a caregiver to her 85-year old husband who was kept alive with a pacemaker. Butler captures her individual experience and relates it to the broader, societal questions about how our healthcare system approaches end-of-life care. For more information, visit: [New York Times Magazine: "What Broke My Father's Heart"](#)

3) Spousal Caregiver Challenges

An article published in the *Washington Post* on May 25, 2010 and drawn from *Kaiser Health News*, highlights the challenges older spouses face in caring for

their partners, especially when they have their own age-related health concerns to deal with. The article notes that spousal caregivers are often reluctant to seek outside help, even from their adult children, and therefore often face more adverse consequences to their own health due to the stress. For more information, visit: [Washington Post: "Spouses face challenges in caring for themselves and their ailing partners"](#)

4) Caregiver Blogs About Experience to Highlight Need for Paid Sick Days

A recent blog posting by Kate Karpilow, Executive Director of the California Center for Research on Women and Families, uses her personal experience as a caregiver to make the case for paid sick days nationwide. While picking up medicine for her mother with congestive heart failure, the author noticed that the pharmacy clerk appeared to have the flu, and when confronted, the clerk admitted that she was sick but did not have paid sick leave because she was a contract worker. While the author ended up going to another clerk, she uses this example to highlight the need for paid sick leave for all employees. For more information, visit: [Huffington Post: "Success in San Francisco with Paid Sick Days"](#)

5) Newsweek: "The Caregiving Boomerang"

An article in *Newsweek* by Gail Sheehy, "The Caregiving Boomerang," highlights the experience of becoming a family caregiver, and it provides advice for those who are in the caregiving role. Sheehy explains the challenges of managing family relationships and the health problems that often result from the stress of caregiving. Sheehy is the author of *Passages in Caregiving: Turning Chaos into Confidence*. For more information, visit: [Newsweek: "The Caregiving Boomerang"](#)

6) Families of Wartime Veterans May Miss a Little-Known Benefit for Long-Term-Care

An article in the *Wall Street Journal* focuses on a little-known benefit to help families of wartime veterans pay for long-term-care. The aid-and-attendance benefit pays a monthly benefit of up to \$1,949 a month to married veterans who qualify. Veterans must meet certain thresholds for medical and financial need. Almost 105,000 veterans were using the benefit as of last year, along with a large number of widows, according to the VA. Potential recipients could be much higher, according to VA estimates, there are 2.3 million veterans from World War II; 2.6 million veterans who served in Korea, and 7.7 million Vietnam veterans. For more information, visit: [Wall Street Journal: "War: One Thing It's Good For"](#)

7) A Growing Number of Families are Compensating Relatives

An article in the *Wall Street Journal* focuses on a growing trend of families compensating relatives who are serving as caregivers. The article highlights ways to avoid family tensions while also complying with Medicaid eligibility requirement problems by drafting a formal employment agreement documenting a caregiver's responsibilities and hours and rate of pay. The authors suggest that the contract should be in line with local practices and also suggest sharing the personal-care contract with the entire family.

[Nolo: Sample Elder Care Agreement](#)

[The Wall Street Journal: "Compensating a Family Caregiver"](#)

8) Property Taxes Popular in Michigan to Support Seniors

A recent article in the *Detroit Free Press* focuses on the popularity of millage (property) taxes to support senior services at the county level. Sixty-three of Michigan's 83 counties have a millage, but for counties without a millage, senior centers and programs supporting seniors rely on state and federal money and unpredictable funding from the general fund of local governments. In contrast, in Rochester, Rochester Hills, and Oakland Township, voters approved a millage in 1982 to fund senior programs. This tax funds the Older Person's Commission and the Older Person's Center, a 90,000 square foot center with lap and therapeutic pools, fountains, and recreational activities. The authors explain that a homeowner with a house valued at \$200,000 would pay about \$25 a year for this tax. In recent August election primaries, 45 millages for senior citizens were renewed and even increased. For more information, visit: [Detroit Free Press: "Carrying Senior Load in Michigan"](#)

"A think tank reviewed 623 ballot proposals in Michigan on a range of issues and found that voters passed every single ballot initiative for senior citizens."

9) Canada: Cost of Caregiving is a Greater Burden for Women

Mary Ann Jenkins is a 56-year-old financial planner from Cranbrook, B.C., and a "sandwich boomer," which means she's providing support for two children and four parents in their 80s. Jenkins is about five years from retirement, but will not be able to slow down because of costs associated with being a caregiver. An Investors Group poll cited by the author of this article reveals that 10 percent of baby boomers with children also provide support to their aging parents. Caregivers in Canada who provide financial assistance report spending nearly \$500 a month and a quarter of them are reducing their retirement savings to cover those costs. According to data from Statistics Canada, three-quarters of caregivers for seniors are women, making women more likely than men to quit their jobs or reduce their work hours, therefore reducing the amount women can save for retirement. Women live longer than men and are more likely to marry people who are older than themselves, and research shows they should actually be saving 20 to 25 percent more for their retirement than men - a six-figure sum for the average middle-class worker. According to a TD Waterhouse poll of female investors, a third of Canadian women are not currently contributing to a registered retirement savings plans, citing a lack of extra money (68 percent) as the top reason for not saving. Fourteen years ago, Amy D'Aprix put a promising career as a Gerontological Social Worker on the backburner when her mother had a stroke. She was driving five hours each weekend to her parent's house to help. "It greatly impacted everything in my life. It took a lot longer to get my doctorate done. I turned down a lot of work during that time because I knew this was a limited time period," she said. Her advice from experience is, "I think this whole issue of caregiving needs to be built into thinking about retirement." For more information, visit:

[The Globe And Mail: "Women, as main caregivers, take a hit in retirement"](#)

Conclusion

This guide provides a broad overview of the types of issues faced by caregivers and the laws, programs, and research that aims to address these issues. Looking forward to 2011, it appears that legal maneuverings around the Affordable Care Act will likely continue until the legality of the individual mandate is decided by the U.S. Supreme Court. Meanwhile, starting January 1, 2010, and for the next 19 years, 10,000 baby boomers will reach age 65 every day, according to Pew Research Center population projections. This shift in demographics means that by 2030, eighteen percent (almost one in five) of the U.S. population will be aged 65 or older.³⁹ Family caregivers provide the majority of long-term care in the U.S. and legislation, funding, programming, and research that recognizes, assesses, and supports family caregivers will continue to be a vital component in this country's long-term healthcare strategy.

“Meanwhile, starting January 1, 2010, and for the next 19 years, 10,000 baby boomers will reach age 65 every day, according to Pew Research Center population projections.”

³⁹ Pew Research Center. 10,000 - Baby Boomers Retire. Retrieved from: <http://pewresearch.org/databank/dailynumber/?NumberID=1150>

Family Caregiver Alliance National Center on Caregiving Resources

Family Caregiver Alliance publishes free fact sheets on some of the most common issues faced by family caregivers. A sampling of our most popular fact sheets is listed below and a full listing of our fact sheets (also available in Spanish and Chinese) is available at our [Web site - caregiver.org](http://www.caregiver.org).

Care of the Caregiver

- [Caregiving and Depression](#)
- [End-of-Life Decision Making](#)
- [Hiring In-Home Help](#)
- [Holding a Family Meeting](#)
- [Making Choices about Everyday Care](#)
- [Taking Care of YOU: Self-Care for Family Caregivers](#)

Health Issues

- [Caregiver's Guide to Understanding Dementia Behaviors](#)
- [Dementia—Is This Dementia and What Does It Mean?](#)
- [Dementia with Lewey Bodies](#)
- [Huntington's Disease](#)
- [Stroke](#)
- [Traumatic Brain Injury](#)

Legal Issues/Planning

- [Dementia & Driving](#)
- [Durable Powers of Attorney and Revocable Living Trusts](#)
- [Legal Issues for LGBT Caregivers](#)
- [Legal Issues in Planning for Incapacity](#)
- [Protective Proceedings: Guardianships and Conservatorships](#)

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Connections- This quarterly newsletter focuses on information, education, support and services for family caregivers.

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