Through the Eyes of the Caregiver

Family Caregiving 2011 Year in Review:
A Compilation of Research, Programs, Legislation & Media Coverage

“...You will need the patience of a saint, the mind of a doctor, and the strength of Hercules—to take care of your loved one.”

- Family Caregiver
Newhall, CA

March 2012
You can download the full report, “Through the Eyes of the Caregiver - Family Caregiving 2011 Year in Review: A Compilation of Research, Programs, Legislation & Media Coverage” at the Family Caregiver Alliance website: www.caregiver.org
Family Caregiver Alliance and the National Center on Caregiving

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

This is our second “year in review” of developments in family caregiving, and there remains considerable room for improvement in how this nation supports the over 42 million family caregivers (and growing) who provide an estimated $450 billion in “free” care annually.1 The majority of this compilation is not original content and the primary sources are cited and hyper-linked throughout the report. FCA thanks all of the authors, media, and researchers who focused on family caregiving in 2011, as well as the family caregivers and the organizations, government programs, and the people who work with caregivers and their loved ones every day. As part of this review, FCA is also releasing our “Best Of” awards for 2011 to recognize some of the best work that focused on family caregivers.

**Federal developments:** Demonstrations and initiatives included in the Affordable Care Act continue moving forward, with a recent poll finding the most popular provision is a requirement that health plans provide consumers with a short, easy to understand description of their benefits and coverage.2 While the Community Living Assistance Services and Support (CLASS) program was “paused,” paying for long-term care continues to challenge families every day.

Several federal bills were introduced, including a re-authorization of the Older Americans Act that would provide grant funding for state Area Agencies on Aging to conduct caregiver assessments. President Obama signed the National Alzheimer’s Project Act (NAPA) in January 2011, and the 132 listening sessions, held around the country allowed Americans to provide input on how this disease affects people and their family and friends who care for them.3

**State developments:** The federal stimulus funding is now extinguished, and many states continued cutting funding for services for the elderly and disabled, though some cuts were challenged in the courts. Positive developments included Pennsylvania updating its Family Caregiver Support Act, and Connecticut, Seattle, and Philadelphia enacting legislation to require paid sick days.

Legislation was also introduced (though many bills were not enacted) that would have strengthened paid sick leave; provided stronger regulation of long-term care insurance, strengthened oversight of assisted living facilities; addressed elder abuse; and required more training and background checks of direct care workers.

**Advocacy:** Throughout the year, caregivers and advocates spoke their mind about the challenges of caregiving and how to improve the nation’s infrastructure. The year ended with an AARP Forum where the majority of speakers had first-hand experience and discussed how to build a groundswell of support to push policy changes. Jonathan Rauch suggested starting an “Occupy Elder Care” movement while Dr. Peter Rabins labeled the current hospital discharge process “a national disgrace.” Jane Gross finished 2011 by asking if family caregivers are “mad as hell?”4

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Federal Introduction

The Affordable Care Act continued to command attention in 2011 as more states moved forward with demonstrations, setting up exchanges, and continuing a trend of shifting money from institutional care to home and community-based services. While CMS re-inserted a provision that would have provided Medicare reimbursement to doctors for discussing end-of-life preferences with their patients, the provision was removed again at the beginning of January, 2011. The Supreme Court announced in December that it would hear three challenges to the Affordable Care Act in March 2012, including the individual mandate.

The federal budget also dominated the conversation in 2011. In April, President Obama and Congress avoided a shut-down of the federal government by making about $38 billion worth of cuts to the FY 2011 budget. In July, President Obama and Congress agreed to a last-minute deal to raise the nation’s debt ceiling along with an agreement to make $2 trillion in federal spending cuts in the next decade. The Supercommittee, charged with finding $1.2 trillion in cuts, was unable to resolve differences over raising revenues and cutting budgets. Theoretically, this means automatic cuts beginning in 2013 of 50% to the defense budget and 50% to other programs, excluding Medicaid, Social Security, and most of Medicare.

Vice President Biden’s “Caregiver Initiative” (an additional $102 million in support of caregiving programs) was not funded for a second year in a row and the $120 million originally allocated for the CLASS program was eliminated for FY 2012. The FY 2012 budget kept funding levels from FY 2011, though Title IV funding (research in aging) was eliminated, funding for the Alzheimer's Disease Demonstrations was reduced 65%, and LIHEAP funding was reduced $1.2 billion from FY 2011.

Dr. Donald Berwick, the chief administrator of CMS, who spread a message of “improving patient experience, improving population health, and reducing costs”, resigned in November and President Obama nominated Marilyn Tavenner as his replacement.

2011 marked the twelfth anniversary of the U.S. Supreme Court’s Olmstead v. L.C. decision, a ruling that requires states to ensure that people with disabilities receive services in the most integrated setting possible. At a meeting with one of the original plaintiffs, President Obama noted that the Department of Justice had joined or started litigation in over 25 cases in 17 states during the prior two years to ensure that the ruling was being followed by states. Meanwhile, Kathy Greenlee, the Assistant Secretary of Aging, highlighted new grants for the Lifespan Respite Care Program as well as a grant that will accelerate consumer direction. Senator Tom Harkin (D-IA) and Representative Cathy McMorris Rodgers (R-WA) wrote an Op-Ed advocating changes to modernize Medicaid,

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citing the average cost of $137,000 to serve a person with an intellectual disability in an institution, compared to $44,000 if the person lived and received supportive services in a community.\textsuperscript{12}

The CLASS Act was originally included in the Affordable Care Act and was intended to address the current lack of long-term care planning or financing by most Americans.\textsuperscript{13} Once a person was enrolled and vested, if they became disabled and needed assistance with activities of daily living, they would have been eligible for at least $50 per day to pay for supportive services, including hiring friends or family, or paying for in-home support.

For 19 months, the Administration on Aging modeled a variety of policies and designs to ensure that it would be self-sustaining. However, in October 2011, Secretary Sebelius announced the suspension of CLASS, citing difficulty with designing the program while staying within the parameters of the law, and keeping the program self-sustaining. FCA has gathered the key reports focused on CLASS on the “Class Round-up Page.” While CLASS is “paused,” families still face sticker shock as they try to navigate long-term care options for their loved ones.\textsuperscript{14}

Federal Legislation and Hearings: The Senate Special Committee on Aging and several other committees held hearings on topics including the reauthorization of the Older Americans Act\textsuperscript{15}, elder abuse\textsuperscript{16}, the Senior Community Services Employment Program\textsuperscript{17} and the CLASS program.\textsuperscript{18} Senators Kohl (D-WI) and Mikulski (D-MD) introduced legislation as part of the Older Americans Act that would implement a grant program to allow state Area Agencies on Aging to conduct caregiver assessments while Senator Franken’s (D-MN) version includes a Home Care Consumer Bill of Rights.\textsuperscript{19}

The Older Americans Act has not yet been re-authorized, but several versions of bills have been introduced. The importance of programs funded by this Act and their impact on older Americans, especially the most vulnerable, has been highlighted throughout the year by the National Council on Aging’s “One Away” campaign.

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Family Caregivers and the Affordable Care Act

While much of the focus of the Affordable Care Act is on improving quality of care for the patient, there is a growing recognition of family caregivers as members of the healthcare team.

Research Brief Focuses on Family Caregivers in Affordable Care Act

A research brief from AARP Public Policy Institute focuses on family caregivers and their inclusion in the Affordable Care Act, with 46 mentions of "caregiver" and 11 mentions of "family caregiver." The law includes measures and surveys to better assess both the patient and their family caregiver's level of satisfaction with care received and promotes shared decision making with medical professionals, the patient, and the family caregiver. For example, the new Innovations Center at CMS will test models that assist family caregivers and their loved ones in understanding medical treatment options. Several pilots and demonstrations (for example, the Community First Choice Option) will benefit caregivers. In addition, the extension of Medicaid spousal impoverishment policies to also include people receiving Medicaid HCBS will take effect in 2014.

AARP PPI "Health Reform Law Creates New Opportunities to Better Recognize and Support Family Caregivers"

Long Term Services and Supports Opportunities in Affordable Care Act

A technical assistance brief from the Center for Health Care Strategies provides an outline of the Money Follows the Person, Balanced Incentives Payment Program, the Community First Choice Option, and the modified Home and Community-Based State Plan option. For each program, the authors outline the budget impact/FMAP opportunity, application process, participant eligibility, care coordination/plans, and data reporting/evaluation of each demonstration or program. CHCS: "Long-Term Services and Supports Opportunities in the Affordable Care Act"

Families USA Guide Addresses Benefits for Caregivers in Affordable Care Act

Families USA released an 8-page guide intended for consumers that addresses provisions within the Affordable Care Act (ACA) that benefit family caregivers. For example, states will have the option to apply for the State Balancing Incentive Payments Program as well as the Community First Choice Option, both of which allow states to increase home and community-based services in Medicaid in exchange for additional federal money. The ACA also includes the Elder Justice Act, Nursing Home Transparency and Improvement Act, and the Patient Safety and Abuse Prevention Act. Families USA: "The Health Care Law: Good News for Caregivers"

Demonstrations, Pilots, and Initiatives in the Affordable Care Act

Partnership to Reduce Hospital Acquired Conditions and Improve Patient Transitions

The Obama administration launched a public/private partnership campaign, "Partnership for Patients: Better Care, Lower Costs," that is intended to decrease preventable hospital-acquired conditions as well as preventable complications that occur when a patient transitions from one care setting to another. Citing the landmark Institute of Medicine study from 1999 ("To Err is Human"), officials hope to address the estimated 98,000 Americans who die every year from preventable medical errors. While the initiative is designed to improve care, it also has the potential to reduce costs, for example, the one in five Medicare beneficiaries who are readmitted to the hospital within 30 days of discharge is estimated to cost $26 billion every year.

Officials hope to address the estimated 98,000 Americans who die every year from preventable medical errors.

Through the Partnership, CMS awarded $218 million to 26 state, regional, national, or hospital systems organizations to be Hospital Engagement Networks that will work to reduce health care acquired conditions and disseminate their work to other health care providers. Ten million dollars was awarded to three organizations to create a patient safety curriculum for the Hospital Engagement Network and engage other stakeholders in support of the Partnership, and to evaluate the impact and effectiveness of the partnership.

In April 2011, CMS announced that it would begin accepting proposals for the Community-based Care Transitions program. Through the program, healthcare and community social service providers can work together and receive Medicare funding to coordinate care transitions. Seven partnerships were awarded funding in
November, and CMS projects accepting applications on an ongoing basis through the first half of 2012. CMS Community-based Care Transitions Program HHS: "Up to $500 million in Affordable Care Act funding will help health providers improve care"

“Preventable” Readmissions
One aim of the Affordable Care Act is to reduce the number of patients who return to a hospital within 30 days of their discharge. Under final rules issued by the federal government in August 2011 (as part of the Affordable Care Act), hospitals will begin to be penalized financially in October 2012 when patients with heart attacks, heart failure or pneumonia (three conditions with the highest rates of readmission) return to a hospital within 30 days. The federal government awarded grants in six states to partnerships under the Community Based Care Transitions program that will partner community-based organizations with hospitals to better coordinate care after discharge.

Hospitals Will Be Penalized For Higher Readmission Rates
Kaiser Health News reports that starting in October 2012, hospitals with the highest readmissions rates could lose up to three percent of their Medicare payments. Medicare will also potentially pay less to hospitals whose patients have higher-than-average costs for patient care by calculating the costs incurred during their stay as well as any costs within 90 days after discharge. Hospital representatives have expressed concerns that the new rules could penalize hospitals for issues out of their control- for example whether or not a patient follows through to obtain a prescription. Hospitals serving low-income patients have also cited concerns with additional challenges with their patients leading to higher readmission rates and a Kaiser Health News study suggests that hospitals with the largest share of poor patients were 2.7 times as likely to have high readmission rates. Trinity Health is highlighted for its work at the 50 hospitals it owns where nurses set up doctor appointments prior to a patient's discharge and also confirm that patients have the ability to get to the appointment. Kaiser Health News: "Medicare Prepares Rule To Penalize Hospitals With High Readmission Rates"

Six States Receive Community Based Care Transition Program Grants
Partnerships in six states (GA, OH, ME, AZ, MA, IL) were awarded grants under the Community Based Care Transition Program (CCTP), a demonstration that is part of the Affordable Care Act. Through the program, community-based organizations (CBOs) are partnering with acute care hospitals to implement care transition interventions for people with Medicare who are at high risk of hospital readmission. The goal of the three-year program is to reduce hospital readmissions, test sustainable funding streams for care transitions, and to save money in the Medicare program. CCTP is part of a broader federal campaign, the Partnership for Patients, which aims to reduce hospital-acquired conditions by 40% and hospital readmissions by 20% by 2013.

CMS: "First Site Selections for the Community Based Care Transitions Program November 18, 2011"

Ohio: Akron-Canton AAA Partners with Hospitals to Reduce Readmissions
An article in the Akron-Beacon Journal Online highlights how a local area agency on aging is partnering with 10 hospitals located nearby to prevent hospital readmissions. The Akron-Canton Area Agency on Aging will provide health coaches who will begin working with patients before they leave the hospital and will continue to follow up with the patient after discharge. The two-year contract with CMS will provide reimbursement to the Akron-Canton Area Agency on Aging for each patient that works with a transition coach and there is the possibility of renewing the contract for another three years. Akron-Beacon Journal Online: “Region lands federal contract to reduce hospital readmissions”

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Florida: Hospitals and Nursing Homes Work To Reduce Readmissions

The St. Petersburg Times recently focused on partnerships in Florida between nursing homes and hospitals in an effort to address preventable readmissions to hospitals. The FL Hospital Association attempted to address readmissions through technology that tracks patients who return to the hospital within 15 days, an initiative that has led to an 11% drop since 2008 in readmissions for heart attack, heart failure, coronary bypass surgery, hip replacement and pneumonia. In Orlando, BayCare Health System studied data on readmissions to its hospitals and found wide variation in readmissions from single digits to more than 80%, and also found that more than half of heart failure patients at one nursing home weren’t being seen by a doctor before being readmitted to the hospital. At St. Anthony’s Hospital, a partnership with a local nursing home addressed readmissions for heart failure patients by screening patients who were at risk for sepsis, essentially eliminating sepsis as a cause of readmissions. A partnership in Tampa Bay is piloting a uniform discharge form with check boxes (to prevent mistakes from illegible handwriting), and a diagram of a body (to identify potential skin sores), with the intent of ensuring that the entire health team is operating with the same information. St. Petersburg Times: "Hospitals, nursing homes team up to cut high readmission rates"

Hospitalists Associated With Shorter Hospital Stays, Increased Medicare Costs

A study in the August 2011 issue of the Annals of Internal Medicine analyzed the increasing role of hospitalists (doctors who work full time in hospitals) and found that for patients who were cared for by hospitalists, their lengths of stay were about a half day shorter and led to charges for the hospital that were $282 lower. However, Medicare costs in the 30 days after discharge were $332 higher, patients were less likely to be discharged to home, and were more likely to have ER visits and readmissions after discharge. The results were based on a 5% national sample of 58,000 enrollees in Medicare parts A and B with a primary care physician who were cared for by their primary care physician or by a hospitalist during a medical hospitalization from 2001 to 2006. In a posting about the results, Jane Gross suggests that generalizing the study’s finding to the roughly 25% of Medicare beneficiaries cared for by hospitalists equates to hospital savings of around $1 billion a year, but that an equal or greater amount is being paid for by taxpayers in the form of higher readmissions. New York Times: "Do Hospitalists Save Money?"

Annals of Internal Medicine: "Association of Hospitalist Care With Medical Utilization After Discharge: Evidence of Cost Shift From a Cohort Study" (abstract is free)

Focus on Dual Eligibles

Policymakers continued their focus on people who are eligible for Medicaid and Medicare (dual eligibles) because of the disproportionate amount of money spent on this population and the fragmented care beneficiaries receive when Medicare and Medicaid don’t function well together.

The Federal Coordinated Health Care Office (also known as the Medicare-Medicaid Coordination office) was created by the Affordable Care Act and is overseeing efforts to improve care for dual eligibles.

In April, 2011, fifteen states received funding from the Center for Medicare and Medicaid Innovation (another program within CMS created by the Affordable Care Act, which is focused on improving care and health while lowering costs24) of up to $1 million each to develop service delivery and payment models to better integrate care for dual eligibles.25

In July 2011, CMS announced additional opportunities for states to better align care for dual eligibles through stronger integration of benefits and financing, and 37 states (including the 15 who were awarded integrated care design contracts) submitted letters of intent expressing interest. A brief from the Kaiser Commission on Medicaid and the Uninsured provides information on the 37 states and Washington, DC. CMS will allow states to select a capitated model (between the state, CMS, and participating health plans), or a managed fee-

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for-service model (between CMS and the state), or states can use both models. This brief includes a chart explaining the main differences between the two models for: responsible entities, benefits package, provider network adequacy, benefits financing, and shared savings arrangement between CMS and the state.


Gaps in Care for Dual Eligibles
A report by the National Senior Citizens Law Center focuses on four areas of Medicare and Medicaid where the programs intersect and gaps occur. These include durable medical equipment, prescription drugs, skilled nursing services, and language access. The authors provide suggestions that they believe could be implemented without broad system overhauls, including: revising authorization procedures for both programs around medical equipment; better transfer of data between the two programs to prevent gaps in prescription drug coverage; collecting and using data on language preferences; improving transition policies (especially for Medicaid beneficiaries who become eligible for Medicare); and better enforcement of existing laws around language services in both programs and especially in rehabilitation services in skilled nursing facilities.

National Senior Citizens Law Center: "Medicare and Medicaid Alignment: Challenges and Opportunities for Serving Dual Eligibles"

Four Briefs Focus on Improvements for Integrated Care Models for Dual Eligibles
The National Senior Citizens Law Center released four briefs focused on efforts to integrate care for dual eligibles. The briefs include:

- Consumer Protection for Dual Eligibles Important in New Integrated Care Models
- Building an Integrated Appeals System for Dual Eligibles
- Medicare and Medicaid Alignment: Challenges and Opportunities for Serving Dual Eligibles
- Improving the Qualified Medicare Beneficiary Program for Dual Eligibles

Dual Eligibles and Medicaid Assisted Living Policies
The National Senior Citizens Law Center’s study, the “Medicaid Payment for Assisted Living Policy Issues Brief Series” focuses on federal and state Medicaid policies for assisted living, with a focus on how these policies affect dual eligibles. The research includes a survey of beneficiaries in 37 states that pay for assisted living services through an HCBS waiver. Additional publications focus on asset transfers, the practice of institutions refusing applicants with greater care needs or whose care is paid for by Medicaid, the medically needy eligibility requirements, and the practice of assisted living facilities attempting to obtain payment from families beyond reimbursement received from Medicaid and/or SSI. http://medicaidalseries.org/

Focus Groups with Dual Eligibles in Five Models of Care
The AARP Public Policy Institute conducted ten focus groups of 77 dual eligibles (total) in five types of care models to better understand their perspectives. Focus groups discussed satisfaction with care received, access to care and providers, coordination of care, navigation of the Medicare and Medicaid appeals process, and communication between providers. The participants were aged 65 or older, had no cognitive impairments, were managing multiple chronic conditions, and about 50% had a recent interaction with a hospital. The results of the focus group were discussed at a December 2011 briefing, where the results from another set of focus groups (conducted by CMS with 156 participants, most aged 18-64 years old), was also presented.

AARP Public Policy Institute: “Experienced Voices: What Do Dual Eligibles Want From Their Care? Insights from Focus Groups with Older Adults Enrolled in Both Medicare and Medicaid”

Alliance for Health Reform and AARP Public Policy Institute Briefing: “Integrating Care for Dual Eligibles: What Do Consumers Want?”

"Selling" Value of Integrated Care to Stakeholders
A guide from the Center for Health Care Strategies, Inc provides a roadmap for state officials who are considering integrating care for dual eligibles. The author explains that finding dually eligible stakeholders may necessitate increased outreach beyond groups that usually provide input. Options for communicating with stakeholders include meetings, webinars, focus groups, project-specific websites, and Requests for Information.

CHCS: "Communicating the Value of Integrated Care to Stakeholders"

Independence at Home Demonstration
In December, 2011, CMS announced that it was accepting applications for the Independence at Home demonstration for up to 50 practices and 10,000 patients. Under the three-year demonstration, patients with multiple chronic illnesses will receive primary care in their homes, with a goal of improving coordination and quality of care while lowering cost. Practices that meet
quality measures and generate savings will be eligible to receive incentive payments.\textsuperscript{26}

\textbf{Accountable Care Organizations}

The federal government announced final rules for Accountable Care Organizations (ACOs) in October 2011. ACOs are designed to increase coordination of health care between healthcare providers, and in return for meeting quality measures and saving money, healthcare providers will share in some of the savings. Between 50 and 270 ACOs are expected to form in the next three years, expected to affect two million Medicare beneficiaries.\textsuperscript{27} There are three types of ACOs, including the Medicare Shared Savings Program—a fee-for-service program, the Advance Payment Initiative—for certain eligible providers in the Shared Savings Program and the Pioneer ACO Model—population-based payment initiative for health care organizations and providers already experienced in coordinating care for patients across care settings.\textsuperscript{28} In December 2011, HHS announced that 32 health systems had been selected as Pioneer ACOs and would begin work as ACOs in January 2012. Pioneer ACOs are designed for groups of providers that already have experience working together to coordinate care.\textsuperscript{29}

\textbf{164 Accountable Care Organizations}

A report by Leavitt Partners estimates that there are 164 ACO's, an estimate based on researching press releases, media reports, and interviews. Organizations were included in the ACO count if they self-identified as an ACO or if they were "adopting the tenets of accountable care." Of the 164 ACO's, 99 were sponsored by hospital systems, 38 by physician groups, and 27 by insurers. The author note that poor and rural regions showed little ACO growth.


\textsuperscript{28}Centers for Medicare and Medicaid Services. What’s an ACO?. Retrieved from \url{http://www.cms.gov/aco/}


\textbf{Leavitt Partners: "Growth and Dispersion of Accountable Care Organizations"}

\textbf{CareMore Profiled for ACO-Like Approach}

The November 2011 issue of The Atlantic features a profile of CareMore, a company that runs 26 care centers across the Southwest. CareMore, founded by a doctor, has focused on providing transportation, using technology for monitoring, and using preventative strategies to improve health care while reducing costs. Company leaders noticed that as many as 1/3 of patients were not attending their doctor's appointments and so the company began hiring car-service companies to get patients to their appointments. Other strategies include home visits, creating a wound clinic (to provide intense care for diabetic patients with small cuts, thus avoiding amputations), and monitoring through wireless weight scales and wireless blood-pressure cuffs that transit data from the patient’s home back to the company. \textit{The Atlantic: "The Quiet Health-Care Revolution"}

\textbf{Accountable Care Implementation Collaborative}

An article in the January 2011 issue of Health Affairs describes the Accountable Care Implementation Collaborative, a group of 25 health systems that paid $150,000 to work on an ACO-like approach. Through the collaborative, members receive technical assistance on implementing an ACO approach. \textit{Health Affairs: “Driving Population Health Through Accountable Care Organizations” (abstract is free)}

\textbf{Report: Rationale for ACO’s, Promising Models for ACOs}

A report from the Commonwealth Fund Commission on a High Performance Health System explains the rationale for creating ACO’s, describes several potential ACO models, and provides recommendations on the implementation of ACOs. \textit{Commonwealth Fund Commission on a High Performance Health System: “High Performance Accountable Care: Building on Success and Learning from Experience”}

\textbf{Patient-Centered Medical Home Model}

The patient-centered medical home is a concept that attempts to make a doctor’s office more accessible for patients, through extended hours, greater access via email or phone, and includes more of a “team-approach” to a patient’s care.\textsuperscript{30}

\textsuperscript{30}Berenson, R., Devers, K., Burton, R. (2011, August). Will the Patient Centered Medical Home Transform the Delivery of
MD: Patient-Centered Medical Home Program Pilot Profiled

The Washington Post profiled a primary care practice in Maryland that is taking part in a federal pilot program (along with 51 other primary care practices) to provide a patient-centered medical home. The focus of the program, which serves about 45,000 patients and started in May 2011, is to improve the quality of care provided through greater coordination with patients, including longer office hours, same-day appointments for urgent appointments, using electronic health records, and a team approach to coordinating care, which includes following up on referrals. This approach is more costly, though a doctor interviewed estimates that the practice will receive about $300,000 in payments through the program (in 2011) that will help pay for new technologies and staff.

Washington Post: "New Maryland health program promotes care for the whole patient"

See Also:
Agency for Healthcare Research and Quality: Patient Centered Medical Home Resource Center

Health Affairs: “Transforming Physician Practices To Patient-Centered Medical Homes: Lessons From The National Demonstration Project” (March 2011)

National Academy for State Health Policy: “Building Medical Homes: Lessons from Eight States with Emerging Programs” (December 2011)

NJ.com “With patient at center, new approach in New Jersey promises better health” (January 2011)

United Hospital Fund: “The Patient-Centered Medical Home: Taking a Model to Scale in New York State” (November 2011)

Urban Institute: “Will the Patient-Centered Medical Home Transform the Delivery of Health Care?” (August 2011)

Money Follows the Person

Money Follows the Person Program Continued through 2016

Secretary Sebelius announced in February 2011 that 13 additional states joined 29 states that are already operating Money Follows the Person (MFP) program. MFP was set to expire in FY 2011, but was extended by the Affordable Care Act until 2016. MFP is designed to assist elderly and disabled people to transition out of institutional care and into community living with supportive services. According to HHS, 12,000 people have moved out of institutional care since the start of the program, and an additional 13,000 people are expected to transition as a result of the grants, which will total more than $621 million through 2016.31

Progress and Delays with Money Follows the Person Program

According to a report from the Kaiser Commission on Medicaid and the Uninsured, the Money Follows the Person (MFP) program was started in 2006 with a goal of transitioning 38,000 people from institutional care to community care, however, as of July 2010, only 9,000 people have been transitioned out of community care. Affordable housing was cited as a large impediment to transitioning more people. With the extension of the program, eligibility rules were also changed, and participants are now eligible for MFP after receiving institutional care for only 90 days, whereas previously they had to receive institutional care for at least six months.

Kaiser Commission on Medicaid and the Uninsured: "Money Follows the Person: A 2010 Snapshot"

Político: "Home care tripped up by red tape"

Update on Money Follows the Person Program

A Kaiser Commission on Medicaid and the Uninsured report provides updated data on the 44 states who are participating in Money Follows the Person (MFP). Based on a survey completed in 2011, almost 17,000 individuals have transitioned back into the community, with 46% of the transitions taking place in Ohio, Texas, and Washington. The average MFP participant is 50 years old, took 4.6 months to transition home, and most often moved into an apartment setting. Affordable housing and workforce capacity (especially direct care workers in rural areas) continue to be challenges for the program and states reported a reinstitutionalization rate of 8.3%. A case study of Georgia's MFP program and profiles from 5 participants in Georgia's MFP program were also published.

Money Follows the Person: A 2011 Survey of Transitions, Services, and Costs

Florida Rejected Two Million Dollar Planning Grant
For Money Follows the Person
A legislative panel in Florida rejected a $2.1 million federal grant that would have started the process for Florida to receive an additional $35.7 million in federal Medicaid funding as part of the Money Follows the Person demonstration program. The five-year program is designed to shift Medicaid beneficiaries out of nursing homes and into home and community-based settings. While Governor Rick Scott recommended accepting the grant, the GOP-majority commission rejected it. The program was expected to result in approximately 1,700 people transferring from nursing homes back into their homes with supportive services.

*Bradenton.com* "Florida panel rejects federal funds for elderly"

**State Developments Affecting Family Caregivers (Not including Medicaid)**

Similar to 2010, a number of laws were introduced at the state level that were never enacted. Legislation was introduced addressing elder abuse, direct care worker background checks, regulation of institutional care, paid leave, and services for Alzheimer’s and other dementias.
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Florida’s Governor Fires LTC Ombudsman, Leading to Investigation and Lawsuit
In February, 2011, Florida’s Governor Rick Scott forced the resignation of the state’s Long-Term Care Ombudsman. Brian Lee was the head of the state’s long-term care ombudsman program and had recently asked Florida nursing homes to provide information about their ownership, which he was empowered to ask under the Affordable Care Act, but which many speculated prompted his firing.32

The Administration on Aging (AOA) announced that it would investigate Lee's firing, and released a report in September 2011 addressing a number of issues with Florida’s Long-term care Ombudsman Program. AOA's report gives the state 30 days to address issues focused on the governor's office interfering with the Long-term Care Ombudsman's office which is in violation of the Older Americans Act. The Miami Herald noted that a day after the report was released, the Miami administrator for the LTC Ombudsman program was fired, despite being described in a June evaluation as "an invaluable employee who is committed to promoting the best care and quality of life for residents."

The Miami-Herald reported that Brian Lee expanded his lawsuit in November 2011 against three organizations. Lee's amended complaint suggests that the Dept. of Elder Affairs and two nursing home trade associations violated a law against interfering with ombudsman activities and Lee also suggests the FL Health Care Association defamed him.

Orlando Sentinel: “Feds to probe ouster of Florida’s nursing-home watchdog”

AOA: "Compliance Review of the State of Florida Long-Term Care Ombudsman Program"

Miami Herald: “Program to protect elders undermined, feds say”

Associated Press"Ex-Fla. nursing home ombudsman's lawsuit expanded"

Indiana Should Pay Family Caregivers through CHOICE and Medicaid
An Op-Ed on July 3 in the Evansville Courier and Press, written by an elder law attorney who is also the president of SWIRCA and More (an Area Agency on Aging), suggests that state leaders in Indiana should consider allowing family caregivers to be paid through the state's CHOICE program or through its Medicaid Waiver. The author, Randall K. Craig, explains that the goal of CHOICE (Community and Home Options to Institutional Care for the Elderly and Disabled) is to allow people to age in their own home. Both CHOICE and the state’s Medicaid waiver program will pay for in-home caregiving by professional caregivers, though Craig suggests that funding is limited. Craig explains that while the population of people aged 65 or older is expected to grow by 90% by 2030, the projected growth in personal care assistance jobs is only 25%, a mismatch in supply and demand that will lead to higher costs for in-home care. Craig suggests that participants in CHOICE and Medicaid waiver programs should be allowed to hire responsible relatives- already an option in other states, and more cost-efficient than institutional care. Evansville Courier and Press: "COMMUNITY COMMENT: Anticipated need for elderly care underscores CHOICE"

Iowa: State Won't Hire Additional Inspectors; CMS Won't Release Data
In July 2011, the Des Moines Register asked the Iowa Department of Inspections and Appeals to release statistical data about nursing homes in the state who fail to meet minimum standards of care. The state contacted CMS, who cited ownership of the data and assumed control of the request, but the newspaper did not receive the data it requested. The newspaper originally filed the request citing an interest in whether Governor Terry Branstad has taken a less punitive approach to regulation of nursing homes. Ten nursing home inspector positions were eliminated earlier in 2011 by Branstad, despite the agency successfully lobbying the state legislature earlier in the year for an additional $650,000 to fill the positions. While the department will still investigate specific complaints, a moratorium extended by the legislature banning routine inspections would have meant that some residential care facilities would not be inspected for four and a half years unless a complaint triggers an inspection. However, in December 2011, the Des Moines Register noted Iowa’s Department of Inspections and Appeals had decided to ignore this moratorium.

Des Moines Register: “Barred inspections of Iowa care sites resume”

Des Moines Register Archive: "Nursing home inspection info withheld from public"

Des Moines Register Archive: "Nursing home inspector money goes elsewhere"

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States continued making cuts to programs serving the elderly and disabled (and their family caregivers) in 2011, and the Center on Budget and Policy Priorities (CBPP) announced in its March analysis of initial budget proposals for FY 2012 that at least 25 states proposed “identifiable, deep cuts in health care.” A July 2011 CBPP analysis found that budget cuts in FY 2012 were the most extreme cuts since the recession began. Out of 44 states for which data was available, 84% (37 states) planned to spend less on services than they spent in 2008.

With a weak economy, more Americans were eligible for Medicaid, placing additional strain on state budgets. While states face difficult budget decisions, for every $1 a state cuts in its Medicaid program, an additional $1.33 is lost in federal funding, for a total loss of $2.33. In January 2011, thirty-three Republican governors signed a letter to President Obama, requesting the ability to cut Medicaid enrollments without losing federal money. In May, CMS announced a proposed rule changing how states analyze the impact of rate cuts to providers in Medicaid. CMS suggested that a standardized methodology would allow for better measuring of access to health care but the proposal was viewed skeptically by some state Medicaid directors.

States were expected to receive $2.8 billion in federal stimulus money in FY 2012, a dramatic reduction from $51 billion in FY 2011 and $60.7 billion in FY 2010. Medicaid accounted for an estimated 22% of total spending in FY 2010, and state funding on Medicaid is expected to increase by 18.6% for FY 2012 while federal funding decreases by 13% due to the expiration of the higher FMAP funding from the Recovery Act.

A June 2011 report by the National Governor’s Association and the National Association of State Budget Officers finds that while state revenues have increased from FY 2011, the additional revenues are insufficient and states face a combined gap of over $75 billion for FY 2012.

The July 2011 agreement to raise the nation’s debt level called for $2 trillion in spending cuts over the next decade, and the Associated Press reported that state policymakers were concerned about potential cuts to programs and/or a reduction in the federal government’s share of Medicaid, known as the FMAP. For example, in Nevada, the federal government pays 55% of the Medicaid bill, and every 1% shift in this ratio would cost the state an estimated $15 million.

The Kaiser Commission on Medicaid and the Uninsured released its 11th annual survey of state Medicaid budgets in October 2011 and the authors explain that unprecedented budget pressures have led states to eliminate, reduce or restrict benefits. In addition, 39 states have lowered provider rates in FY 2011, with 46 states planning lower rates for FY 2012.

Retrieved from
http://www.nytimes.com/2011/05/03/us/politics/03medicaid.html?_r=1&emc=tn&ntemail=y


Resources on State Budgets:

- Center on Budget and Policy Priorities: “Governors are Proposing Further Deep Cuts in Services, Likely Harming Their Economies” (March 2011)
- Center on Budget and Policy Priorities: "State Budget Cuts in the New Fiscal Year Are Unnecessarily Harmful" (July 2011)
- Center on Budget and Policy Priorities: “States Continue to Feel Recession’s Impact” (January 2012)
- US Census Bureau: State Government Finances Summary: 2010 (December 2011)

Overview of State Developments

**Arizona** received permission in February 2011 from the federal government to cut 280,000 low-income, childless adults from the state’s Medicaid program, though state leaders later reduced the amount to 100,000.\(^{42}\)

**California** garnered national headlines when Governor Jerry Brown attempted to dismantle the Adult Day Health Care Centers (ADHCs) by eliminating them as an optional benefit in the state’s Medicaid program, Medi-Cal. When state legislators proposed halving the program’s budget, Governor Brown also vetoed that proposal. A court settlement was announced in December 2011 that would create an ADHC-like program, Community Based Adult Services (CBAS), and a state official estimated that about half of the current ADHC participants would qualify for the new program.\(^{43}\) A 2010 analysis of eliminating ADHC found that the proposal would cost the state $51.6 million with expenses rising to over $412 million by 2040.\(^{44}\)

Brown’s budget proposal also called for cuts to the In Home Support Services (IHSS) that would have resulted in a 12% reduction in hours for over 436,000 IHSS benefits, and cuts within the Multipurpose Senior Services Program (MSSP) to benefits including payment for ADHC, housing assistance, personal care and chore assistance, respite, meal services, and transportation. Governor Brown also proposed copayments of $50 for ER visits and $100 co-pays ($200 maximum) for hospital stays for Medi-Cal beneficiaries, though this proposal was rejected by the federal government.\(^{45}\)

A leaked February 2011 Legislative Analyst Office letter suggested programs to eliminate if taxes weren’t extended, including California’s Caregiver Resource Centers, Adult Protective Services and the Agency on Aging.\(^{46}\) In 2012, Governor Brown once again proposed eliminating the Caregiver Resource Centers.\(^{47}\) A year-long UCLA study followed 33 older adults who receive support from the IHSS program, and participants report that they rely on a patchwork of supports to remain in their homes. The authors note that more cuts to supportive programs could push people into institutional care.\(^{48}\)


Governor Brown signed a budget in March with $11.2 billion in cuts to social service programs, but was unable to garner Republican support to extend state taxes. New America Media contrasted the budget cuts to recommendations in California’s recently released state Alzheimer’s Plan that suggests increasing support for home and community-based services to address the estimated 1.2 million elders in California who will have Alzheimer’s by 2030.49

As part of the enacted budget, so-called “trigger cuts” were to be imposed if state revenues did not meet rosy projections. These cuts included a 20% across-the-board cut to IHSS, however, a federal judge issued a temporary restraining order in December 2011 blocking the cuts, and in January 2012, the same judge ordered attorneys for the state and plaintiffs suing on behalf of IHSS recipients to meet and discuss how best to “word an order” to make more precise cuts.50

Florida was named in a class-action lawsuit in March 2011 on behalf of the 19,000 Floridians with developmental disabilities who have been placed on Medicaid waiting lists that can often take several years. Disability Rights Florida filed the lawsuit, and suggested that because of the state’s system of assigning priority, people on the waiting list may never receive Medicaid services unless their caregiver passes away.51 State officials announced in Florida that as part of a move to privatize the state’s Medicaid program, they were planning to institute monthly Medicaid premiums of $10 per person as well as a $100 co-payment for non-emergency visits to the ER. Joan Alker, a senior researcher at Georgetown University’s Health Policy Institute, explained to Kaiser Health News that: “The most similar experience we can look at is Oregon,” she said. "With respect to adults below poverty, Oregon instituted premiums in 2003 and over the next few years enrollment for adults dropped precipitously from 104,000 to 24,000.”52

Illinois reduced its “Free Rides for Seniors” program that previously provided free rides for seniors aged 65 and older. Under the new rules, only low-income seniors ($27,610 or less for a single person) continued to receive free rides, while “wealthier” seniors would have to pay a reduced fare.53

Iowa Governor Terry Branstad proposed reducing respite hours for caregivers in the state Medicaid program, however, he eventually reversed course and Radio Iowa suggested the reversal may have been due to hundreds of emails sent to the governor by family caregivers.54

Massachusetts proposed cutting 2/3 of funding for the state adult day care programs.55

Mississippi’s Governor Haley Barbour suggested that face-to-face interview requirements in Medicaid “hold down costs and ‘keeps ineligible people off the program’ and that ‘There’s nobody in Mississippi who does not have access to health care.” CBPP analysis suggests that the in-person interviews led to 62,000 fewer children and adults in the program, and cited a 2007 report that found that 90% of “new” Medicaid applications are for families and children whose

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coverage had lapsed, creating a “churning effect” and additional, unnecessary paperwork.\(^57\)

**Nevada** Governor Brian Sandoval proposed to balance the state budget by reducing Medicaid reimbursement rates. The Nevada Health Care Association estimated the move would cost the average Nevada nursing home $500,000 annually, with a total loss to hospitals of $190 million from 2009-2013.\(^58\)

**New Hampshire** Two dining rooms in public housing complexes were closed in July 2011 because of state cuts to the Congregate Services Program that provides meals, housekeeping, laundry, grooming and other services to frail public housing residents. A representative explained that the state may have to close three other programs if the state doesn’t provide a match that “draws down” additional federal funding, and suggested that participants may be forced into more expensive options like Choices for Independence ($18,000 a year) or nursing homes ($101,000 a year).\(^59\) Governor John Lynch also recommended cutting funding for case managers who assist about 500 elderly, poor residents who live in small facilities.\(^60\)

**New Mexico** almost cut the state share ($9 a person) for Food Stamps (SNAP) for 4,000 low-income elderly and disabled residents who receive the minimum federal benefit ($16). The state legislature originally declined to fund the benefit, but eventually reversed course.\(^61\)

**New York** Governor Andrew Cuomo created a panel in 2010 to redesign the state’s Medicaid program in an effort to control spiraling costs.\(^62\) The panel received 3,000 suggestions, and identified 49 potential strategies that have the potential of reducing costs by $4 billion.\(^63\) A report by the United Hospital Fund analyzed Medicaid rate of service use and levels of spending per recipient across New York State and found that spending in New York City accounts for 66% of long-term care spending statewide. New York City also had a significantly lower level of nursing home spending (52%) and higher share of spending on home health services (80%) and personal care (84%).\(^64\)

In November, New York City agreed to pay a $70 million fine to the federal government after a whistle-blower suggested that New York City improperly approved home health care services in its Medicaid program for the past ten years. Advocates for the disabled sent a letter to CMS as well as the United States Attorney for Manhattan (who had originally brought the lawsuit against the city on behalf of the federal government), suggesting that the city is now over-reacting as a result of the suit and starting to reduce or withhold in-home services. In response, the US Attorney suggested that New York State formulates Medicaid policies, and the Department of Justice only enforces them, while a city representative acknowledged that the city was being "more vigilant" as a result of the settlement.\(^65\)

**Oregon** originally considered a 50% reduction to Project Independence in 2011 but later changed course.\(^66\) The Governor ordered a freeze on enrollments in state programs in December 2011, including the Project Independence Program which helps people “age in place” and already had an estimated waiting list of 1,000


people. The program was listed as another possible target for reductions in January 2012.

**Tennessee** was considering eliminating hospice counseling in the state’s Medicaid program at the time of writing.

**Texas** underfunded its Medicaid program by $5 billion in its FY 2012-13 budget.

**Washington State** was ordered by a county judge to pay 22,000 home-care workers $96 million in back pay and accrued interest after a 2003 state decision to pay caregivers 15% less if they lived in the same household as the care recipient who was receiving Medicaid. While the state reversed this policy in 2007, it never reimbursed caregivers for the four years of reduced payments.

**West Virginia** froze enrollment in its Medicaid Aged and Disabled Waiver program in December 2011, effectively creating an enrollment cap of 8,000 clients.

**Wisconsin** enacted a state budget that gives Governor Walker’s administration the ability to remake Wisconsin’s Medicaid program with relatively little legislative oversight. The Department of Health and Services is expected to use this power to find $466 million in savings for the next two years. Advocates interviewed by the *Journal Sentinel* were concerned about the abdication of power by elected representatives, the precedent of giving the power to the administration, and the potential changes that will be made to shave $466 million from the program.

**Medicaid**

As the largest payer of long-term care in the U.S., policies, research, and developments in Medicaid are especially relevant to family caregivers. An October 2011 report noted that while Medicaid long-term care users accounted for six percent of the Medicaid population, they account for nearly half (48%) of total Medicaid spending. While the Affordable Care Act increases incentives for states to shift more spending to home and community-based services (HCBS), there continues to be wide variation among states.

This section is divided into three parts:

1) General research and developments in Medicaid
2) Medicaid Managed Care
3) Home and Community-Based Services, including Olmstead developments.

**Medicaid’s Role in Financing Long-term Care**

A May 2011 fact sheet from the AARP Public Policy Institute gives a high-level overview of Medicaid’s role in paying for long-term care. The authors note: “…nearly a third of people turning age 65 will have costs that exceed their ability to pay and will need Medicaid assistance. Middle-income Americans currently have few options to help them pay for the high cost of LTSS. For those who have spent down their life savings paying for LTSS, Medicaid provides a critical safety net.”

**Medicaid Financing Framework**

An April 2011 issues brief from the Kaiser Commission on Medicaid and the Uninsured provides an overview of Medicaid and its joint-financing structure between states and the federal government. The brief also analyzes
The authors note that states are restricted in their ability to change eligibility or enrollment policies for state expansion enrollees who were eligible as of March 23, 2010 (when the Affordable Care Act was passed) due to the Maintenance of Efforts provisions.

Brief Explains How FMAP is Calculated and Potential Impact of ACA
A paper from the Kaiser Commission on Medicaid and the Uninsured provides an overview of the Federal Medical Assistance Percentage (FMAP), how the formula is calculated, and potential changes as more people become eligible for Medicaid under the Affordable Care Act. FMAP is the specific percent that the federal government pays in calculating its share of the cost of Medicaid in each state and is based on each state's per capita income for the past three years relative to the U.S. average. Because the income is calculated using data from the past three years, there is a lag in accounting for economic downturns. The formula gives relatively poor states a higher share of federal money than wealthier states. On average, the federal government pays about 57% of the cost of Medicaid benefits while states pay 43%.

Kaiser Commission on Medicaid and the Uninsured: "An Overview of Changes in the Federal Medical Assistance Percentages (FMAPs) for Medicaid"

Core vs. State Expansion Spending on Medicaid
A research brief analyzes the "federal core" enrollee groups and mandatory health benefits that all states are required to provide and compares data on this group to "state expansion" enrollees and optional benefits. For example, elderly and disabled individuals receiving SSI (less than 75% of the Federal Poverty Line of $8,168 for an individual) are federal core enrollees, whereas nursing home residents with income above SSI level but below 300% of SSI ($2,022) are state expansion enrollees. In 2007, 40% of Medicaid spending was for federally-required benefits for core enrollees, while 60% of spending was for state expansion enrollees and optional services. Spending on state expansion enrollees (for both mandatory and optional services) accounted for 42% of Medicaid spending in 2007, and almost 80% of this spending was for elderly and disabled individuals. The authors note that states are restricted in their ability

Variation in Medicaid Spending Correlates to Primary Care Access
A study in the July 2011 issue of Health Affairs analyzed Medicaid spending across states from 2001-2005 for inpatient hospital services, outpatient services, and prescription drugs and found wide variation in spending. Spending per-beneficiary in the ten highest-spending states was $1,650 greater than the national average, with 72% of this due to the greater number of services received. The mid-Atlantic region (NJ, NY, PA) had the most expensive care due to high service volume, and to a lesser extent high prices. The South Central region (AL, AR, KY, LA, MS, OK, TN, TX) had the least expensive care. The number of primary care physicians in specific areas was correlated with reduced rates of admissions for diabetes, lung disease, and adult asthma, and the authors suggest that increasing access to these providers help manage common chronic conditions while decreasing spending. Washington state is cited as the best example for lowering Medicaid spending through reduced acute care spending (18% below the national average) and increased access to primary care providers (outpatient visits and prescription fills were 15% above the national average). The study also found that higher numbers of hospital beds and specialists were correlated with higher number of hospital admissions. Health Affairs: "Differences In The Volume Of Services And In Prices Drive Big Variations In Medicaid Spending Among US States And Regions" (abstract is free)

Increased Cost-Sharing Does Not Save Money And May Worsen Health Care
A review of studies of increasing the patient’s share of costs (cost-sharing) found that it often leads to worse health outcomes and does not always achieve cost savings. The findings are especially relevant for state policymakers who may be considering increasing cost-sharing in Medicaid as a way to save money. In a Rand study, higher cost-sharing led to less patient-initiated care for healthier patients, however, this population already has low medical expenses. The study also found that higher cost-sharing led to patients reducing their use of both appropriate and inappropriate care about equally.

For people with chronic conditions that need high amounts of health care, cost-sharing will not necessarily mean a reduction in the amount of care they consume
because their treatments are medically necessary. Additional studies found that "that low-income people in poor health are more likely to suffer adverse health outcomes, such as increased rates of emergency department (ED) use, hospitalizations, admission to nursing homes, and death, when increased cost-sharing causes them to reduce their use of health care, particularly prescription drugs..."

Robert Wood Johnson Foundation: "Cost-sharing: Effects on Spending and Outcomes"

Oregon’s Medicaid Program and Health and Financial Benefits of Enrolling
A working paper from the National Bureau of Economic Research analyzed data on Oregon’s Medicaid program and a lottery in 2008 that was used to triage who could apply for Medicaid. The New York Times explains that the study is considered unique because prior to this study, it was difficult to compare people who had insurance with those who did not. Because people were randomly selected to have Medicaid or not have it, researchers were better able to isolate the effects of having Medicaid coverage. Data from the first year of the collection indicates that the 6,000 people with Medicaid coverage were 35% more likely to visit a clinic or see a doctor, 15% more likely to use prescription drugs, and 30% more likely to be admitted to a hospital than the 6,000 without Medicaid. Those with Medicaid were 25% less likely to have an unpaid bill sent to collections and 40% less likely to borrow money or not pay other bills due to medical bills.

NBER: "The Oregon Health Insurance Experiment: Evidence from the First Year" (Abstract is free)

New York Times: "First Study of Its Kind Shows Benefits of Providing Medical Insurance to Poor"

Rules Impacting LGBT Caregivers
Change
An article in Aging Today discusses recent policy changes that have improved the lives of LGBT elders. Daniel Redman, an attorney with the Elder Law Project of the National Center for Lesbian Rights (NCLR), explains that spousal impoverishment protections in Medicaid don’t apply to same-sex partners, which can have negative financial impacts for LGBT caregivers. Massachusetts implemented spousal impoverishment protections in Medicaid in 2008 for same-sex couples and HHS announced in June that other states could also extend some spousal impoverishment protections to same-sex couples. Redman also addresses an Obama administration announcement from January 2011 that requires all medical facilities receiving Medicaid or Medicare funding to allow patients to choose their own visitors. In addition, HUD guidelines updated this year clarify that "gender identity discrimination" must be treated as gender discrimination under the Fair Housing Act. President Obama said he supports the repeal of the Defense of Marriage Act which currently excludes same-sex partners from 1,100 federal rights, benefits, and privileges. Aging Today "Improving LGBT Lives, One Law at a Time"

HHS Informs States on Options to Equalize Spousal Impoverishment Rules
The Department of Health and Human Services sent a letter to state Medicaid directors, informing them of existing options and flexibility to address rules that often result in uneven financial treatment for same-sex couples by Medicaid. Under current rules, Medicaid can impose liens against the property of a Medicaid beneficiary to recover costs. However, liens may not be imposed if spouses, children under 21 or who are blind or totally/permanently disabled, and siblings are lawfully residing in the home.

HHS notes that this exclusion represents a "floor" from protection against liens and suggests that states have considerable flexibility in determining a "ceiling" for such protections. In other words, states could choose to not pursue liens when same-sex spouse or domestic partner beneficiaries continue to lawfully reside in the home. The letter also addresses asset transfers by Medicaid beneficiaries and explains that state Medicaid policies could address whether or not asset transfer penalties would create an undue hardship on a same-sex spouse or domestic partner. HHS notes that states also have flexibility around estate recovery and applying liens to pay for the assistance a deceased Medicaid beneficiary received. States are required to have procedures to waive estate recovery where it would create an undue hardship for the heirs, and states could include same-sex spouses or domestic parents in these procedures.

A September 2010 Fact Sheet from SAGE, MAP, and CAP, noted that Massachusetts and Vermont extend spousal impoverishment protections to married same-sex couples and that Washington State passed legislation to prevent the recovery of assets transferred to a same-sex or heterosexual domestic partner where a similar asset transfer by a married couple would have been allowed. The
National Resource Center on LGBT Aging recently announced several new resources for LGBT older adults, including an interactive map with state-level legal resources, as well as informative articles on wills, advance directives, and financial power of attorney.

HHS June 10th Letter "Same Sex Partners and Medicaid Liens, Transfers of Assets, and Estate Recovery"

LGBT Older Adults and Long-Term Care under Medicaid

National Resource Center on LGBT Aging Introduces Legal and Financial Support Resources

**Managed Care in Medicaid**

Managed care in Medicaid, including for long-term care, continued to grow at a fast rate in 2011, though advocates questioned if policymakers are including stakeholders in transition planning, if transition timelines are realistic, if sufficient safeguards are included to ensure continued access to doctors, and if data exists to demonstrate that managed care is more cost-efficient than fee-for-service models.\(^{75}\)

**Eight Lessons for Effective Managed Care in Medicaid**

The Center for Health Care Strategies, Inc. cites the growing trend of states using managed care in their Medicaid programs, including for the planned Medicaid expansion in 2014. States are also turning to managed care for vulnerable, high-need, high-cost populations, including children with complex needs, seniors and adults with disabilities, and dually eligible beneficiaries. The author suggests that the most critical “ingredient for success” is for the state to be an active purchaser, and she provides eight lessons for effective managed care, based on the CHCS’ experience during the past 15 years. 

CHCS: “Eight Key Lessons for Managing Care in Medicaid in 2011 and Beyond”

**Most Medicaid Beneficiaries Are Enrolled in Managed Care**

The Kaiser Commission on Medicaid and the Uninsured released results from a survey in September 2011 that focuses on the national trend of states relying on managed care programs to deliver services through Medicaid. Two-thirds of Medicaid beneficiaries (nationally) are enrolled in managed care programs, including risk-based managed care organizations (MCO) and primary care case management programs (PCCM). More than two-thirds of responding states report that Medicaid beneficiaries in MCO’s sometimes experience access problems, especially for dental care, specialists, and other behavioral health providers. However, improved access to primary and specialty care was cited most often as a perceived benefit of managed care (as compared to fee-for-service). Thirty-nine states report that medical home initiatives have been started in their states to better coordinate care for beneficiaries with more complex needs, while over half of states operate PACE sites, with a total national enrollment of about 20,000. Twenty-five states report that dual eligibles are enrolled in Medicaid managed care in 2010, on a voluntary or mandatory basis.

**Kaiser Commission on Medicaid and the Uninsured "A Profile of Medicaid Managed Care Plans in 2010: Findings from a 50-State Survey"**

**Publicly Traded Medicaid Plans Trail Providers Plans**

A June 2011 Commonwealth Fund research brief compared publicly-traded health care plans to provider-sponsored plans. More than 50% of Medicaid enrollees in Florida, Georgia, Illinois, Texas and Washington are in plans owned by publicly-traded, for-profit companies. The non-publicly traded plans scored higher in preventive care, chronic illness care and access to care. Publicly traded plans incurred lower medical costs, and the authors suggest this “may be a function of more cost-effective care, the enrollment of healthier beneficiaries, restricted access to costly medical providers, and/or lower negotiated rates with contracted providers.”

**Commonwealth Fund: “Assessing the Financial Health of Medicaid Managed Care Plans and the Quality of Patient Care They Provide”**

**Stakeholders Provide Suggestions for States Considering Managed Care**

An October 2011 report from the Kaiser Commission on Medicaid and the Uninsured focuses on a growing trend of states using managed care organizations to administer their Medicaid programs and provides suggestions (based on interviews with stakeholders) for state policymakers considering shifting to managed care.

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Kaiser Commission on Medicaid and the Uninsured: "Examining Medicaid Managed Care: Long-Term Service and Support Programs: Key Issues To Consider"

States Should Use Experience with Managed Care to Develop State Health Exchanges
A report from the Center for Health Care Strategies, Inc., suggests that states capitalize on their experiences with Medicaid managed care as they develop their Quality Health Plans (state health exchanges). The authors use contracts in six states (AZ, MN, NY, TN, WA, WI) and examine how the states made decisions about provider networks, quality, accreditation, marketing, information and data disclosure, and plan selection. The authors cite provisions from the Affordable Care Act and highlight where states can “borrow from and align Quality Health Plan standards with Medicaid Managed Care, as well as areas in which MMC requirements are ill suited for adoption in exchanges.” CHCS: “Medicaid Managed Care: How States’ Experience Can Inform Exchange Qualified Health Plan Standards”

Technical Assistance Provided to 10 States to Improve Medicaid LTSS
The Center for Health Care Strategies, Inc. announced in June 2011 that it will provide technical assistance to ten states to improve their Medicaid long-term services and support (LTSS) programs. The ten states include Arizona, Georgia, New Jersey, Nevada, Oklahoma, Pennsylvania, Rhode Island, South Dakota, Virginia, and Washington. The grant is supported by the Scan Foundation, and will allow states to focus on rebalancing their LTSS system to more home and community-based settings and/or focus on managed LTSS. The Affordable Care Act includes incentives for states to improve LTSS, and it is expected that these grants will assist states in improving health care quality, controlling costs, and enhancing quality of life for beneficiaries. CHCS: "Implementing the Roadmaps: Innovations in Long-Term Supports and Services"

State Developments in Medicaid Managed Care
Florida: Managed Care Could Lead to “Granny Dumping”
The Palm Beach Post reported on several meetings held by the state to gather input about the state Medicaid program’s possible transition to a managed care system. The plan would require most of the state’s three million Medicaid enrollees (including seniors in nursing homes) to join private health plans after July 1, 2012. The shift is seen as a way to better manage costs, with enrollment growth increasing 50% in the past four years with a cost that now exceeds the education budget at more than $20 billion. However, patients and advocates are skeptical, and a participant from a pilot of the managed care plan discussed her experience with doctors leaving the system, prescriptions not being filled by plans, and her having to change plans repeatedly.

The shift would require approval from the federal government and is similar to a pilot conducted in five Florida counties. According to the New York Times, a report on the pilot by Georgetown University found that some HMO’s left the pilot program because of low reimbursement rates, leaving beneficiaries in limbo. Critics have also suggested that there was insufficient evidence to analyze if the pilot program improved care while saving money and suggest that Medicaid beneficiaries may have difficulty navigating managed care bureaucracies.

Lawmakers also passed legislation to increase cost-sharing for Medicaid beneficiaries, including a mandatory $10 monthly premium except for nursing home residents and a $100 co-pay for using the ER for "routine care." These fees conflict with existing federal Medicaid law and would need to be approved by the federal government. Dr. Peter Viccellio explained to Kaiser Health News that he believes Medicaid recipients use ERs because they are sicker and have fewer doctors willing to see them. "When you add a co-pay you obstruct access to care for both emergency and non-emergency care," he said. "This is not a way to save money, it's a way to punish people for being poor."

Georgetown University Analysis of Florida Medicaid Pilot

Palm Beach Post: "Lawyers warn of "granny dumping" at Medicaid hearing in West Palm Beach"

New York Times: "In Florida, H.M.O.'s Would Treat Medicaid Patients"

Washington Post: "Fla. pilot program to cut Medicaid costs raises new questions"

Kaiser Health News: "Florida Pushing New Fees for Most Medicaid Recipients"
Illinois: Doctors May Not Join New Plan for Medicaid
An article in the *Chicago Tribune* focused on the potential impact of Illinois’ move to an HMO-style program of care for people with serious disabilities. Rasul “Rocky” Clark, a former high school football player who was paralyzed in a football game is profiled for the care he currently receives at the Ingalls Health System. Under the new plan, expected to affect about 40,000 Illinois residents and save an estimated $200 million over a five year period, patients may or may not have access to doctors they have been seeing. In Clark’s case, he has been the same doctors for the past decade, and his current hospital has not signed up for the new program, meaning Clark may have to travel to a hospital that is 22 miles away. A $5 million insurance policy that had been paying for his medical care reached its cap this year, meaning it will no longer cover his medical care. *Chicago Tribune*: “Paralyzed football player fears for health under new state Medicaid plan”

NJ: Elderly and Disabled Required To Enroll In Medicaid HMO's
*NorthJersey.com* profiled New Jersey’s shift to providing Medicaid through HMO’s, a move that is being duplicated throughout the nation. For existing Medicaid beneficiaries, they will enroll in an HMO that will continue paying their providers, and the HMO will later assess the beneficiary to ensure that they meet eligibility criteria and will negotiate new contracts with the providers. While state officials suggest the change will lead to better coordinated care, less duplicated services, and reduced costs, some advocates are concerned.

The CEO of a home care staffing association expressed concerns that the state did not allow adequate time for the transition and suggested that this could lead to late reimbursements for the companies as billing systems are converted. Nursing homes will receive about $9 less each day for the 29,000 Medicaid residents, which the president of the Health Care Association of New Jersey suggested will lead to a shortfall of about $35 every day for each Medicaid patient. Patients with complex disabilities and medical needs were previously exempted from enrolling in managed care, however, they will now have to enroll in an HMO but will continue receiving their same services until equal care is arranged in their new network. *NorthJersey.com* "Big shifts lie ahead for N.J. Medicaid"

Oregon Governor Suggests Alternative to Managed Care in Medicaid
Oregon Governor John Kitzhaber was profiled on the *Kaiser Health News* blog for attempting to transform Oregon's Medicaid program into a Coordinated Care Organization (CCO). While a number of states are moving to managed care models for Medicaid, this approach, if approved by the federal government, would go beyond solely medical care for a beneficiary, and would also address other issues that can affect health, including transportation or housing. Governor Kitzhaber suggested that “90% of what keeps us healthy is outside the medical system.” Similar to managed care, the state would pay a set fee to the CCO, and the CCO would benefit when patients were kept healthy and out of the hospital. The initiative is planned to launch in July 2012, and if it’s successful, Kitzhaber would like to extend it to state employees and Medicare.

"90% of what keeps us healthy is outside the medical system."

Texas: Politics of Shifting Medicaid to Managed Care
*Kaiser Health News* analyzed the politics, finances, and consumer impact as at least 20 states shift to managed care for their Medicaid programs. Texas is profiled for a shift to managed care in the Rio Grande Valley. While Texas state lawmakers had originally banned Medicaid managed-care from several Texas counties in 2003 (at the urging of doctors and hospitals), this was recently reversed in light of budget difficulties, a *New Yorker* article that focused on high Medicaid costs in McAllen (older and disabled Medicaid patients costs $15,311 a year on average) and an 18-month lobbying campaign by insurers. The authors suggest one issue that may have to be addressed by managed care companies is the area's average spending on home care and related long-term care services; at $4,791 per patient, it’s twice the state's average. *Kaiser Health News/Washington Post: “Insurers See Growing Risks As Well As Revenues In Medicaid Managed Care”*
Home and Community-Based Services

A wide range of research was released on Medicaid HCBS in 2011, with focuses on demonstrations in the Affordable Care Act, waiting lists, rebalancing from institutional care to HCBS, and access issues with HCBS. Note: See map above.\(^{76}\)

In July 2011, the National Resource Center for Participant-Directed Services launched an interactive map that lists consumer-directed programs in each state.\(^{77}\)

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\(^{76}\) HCBS spending includes HCBS expenditures authorized under Sections 1915(c) and 1915(j) of the Social Security Act including MR/DD; the home health benefit; the optional personal care benefit; the Program of All Inclusive Care for the Elderly; and select HCBS expenditures authorized under Section 1115 of the Social Security Act. It does not include HCBS spending under Section 1915(i) of the Social Security Act, spending through managed care programs, or spending authorized under Section 1115 that was not clearly allocated to community-based long-term care. Reliable fee-for-service data do not exist for Arizona and Vermont.

\(^{77}\) National Resource Center for Participant-Directed Services Program Map. Retrieved from: http://web.bc.edu/libtools/insights-publications.php

Expenditures on Medicaid 1915 (c) waivers for FY 2005-2010

Thomson Reuters released a report in October 2011 that provides data on state expenditures for Medicaid 1915(c) waivers. The report provides data for FY 2010 expenditures per waiver, spending for each state from FY 2005-2010, and data by target population. Thomson Reuters: "Medicaid 1915(c) Waiver Expenditures: 2011 Update (October 2011)"

Person-Centered Care Domains of Practice Released

CMS announced in 2009 that it intended to define community living and use a definition across all Medicaid HCBS programs. In response to a notice of these proposed rules, the Center for Excellence in Assisted Living (CEAL) released its recommendations for person-centered HCBS attributes and assisted living indicators in July 2011. The recommendations include attributes for all HCBS settings as well as indicators that are solely for assisted living. The authors explain that "A service planning and operational process that is focused on PC is able to deliver on the core promises of assisted living including: maximizing privacy, autonomy and choice, meaningful access to the surrounding community, experiencing meaningful life and engagement and quality care."

CEAL: "Person-Centered Care Domains of Practice"
Medicaid HCBS and Wait Lists for Programs
A December 2011 data update from the Kaiser Commission on Medicaid and the Uninsured provides updated data on the three main home and community-based services (HCBS) programs, including the 1915 (c) HCBS waiver, Mandatory Home health benefit, and the optional state plan personal care services benefit. The number of individuals on Medicaid waiver waiting lists, increased by 17% from 2009 to 2010. There were a total of 428,571 people on waiting lists in 2010, (an increase of 17% from 2009) with 268,220 on MR/DD wait lists and 121,149 on Aged/Disabled wait lists, and an overall average wait time of 22 months. The authors note that the increase in number of people on wait lists “has implications for states’ compliance with the Olmstead decision.” Kaiser Commission on Medicaid and the Uninsured: "Medicaid Home and Community-Based Services Programs: Data Update" (December 2011)

HHS "Community Living" Listening Sessions
As part of President Obama's "Year of Community Living," (honoring the 10th anniversary of the Olmstead v. L.C. decision), HHS launched the Community Living Initiative to identify strategies to improve services and access for individuals with disabilities and older adults. This initiative included Stakeholder Dialogues and Listening sessions in four states (CA, MA, VA, NC) and HHS released the results of these sessions earlier this month as well as successful strategies and campaigns in these states. The lack of affordable, accessible, and integrated housing was highlighted as a major challenge. Access to services provided through Medicaid waivers was also an issue, with participants suggesting that the current eligibility standards based on diagnostic labels means that people can't access needed services and also contributes to conflicts between groups competing for resources. Adequate training and support for family caregivers as well as direct care providers was also included as a challenge to community living. HHS: "Stakeholder Dialogues Summary Report"

State Options for Expanding HCBS
A report from the Kaiser Commission on Medicaid and the Uninsured examines current options for states to increase the amount of money spent on Home and Community-Based Services (HCBS) as compared to institutional care. While only 38% of Medicaid beneficiaries received institutional long-term care in 2009, this group represented 55% of expenditures, which the authors suggests points to the greater cost-effectiveness of HCBS and the need for rebalancing. One option to increase HCBS is offering Personal Care Services through the state plan instead of through a waiver. The authors also suggest consolidating multiple HCBS waivers (and their managing agencies) and offering HCBS through a state plan as a strategy to reduce administrative costs. The cash and counseling program, offered through a state plan, allows beneficiaries to hire their own providers (including family members) and may also expand access to HCBS. Setting financial and functional eligibility criteria for HCBS at the same level as nursing home care is another strategy. Kaiser Commission on Medicaid and the Uninsured: "State Options That Expand Access to Medicaid Home and Community-Based Services"

Rebalancing HCBS: Strategies, Challenges, and a Research Agenda
A report by the Hilltop Institute addressed rebalancing Home and Community-Based Services (HCBS). The authors explain that the national average on HCBS spending for individuals with intellectual and developmental disabilities has increased considerably to 65.6% spent on HCBS in 2009. For adults aged 65 and older and persons with disabilities, HCBS spending (as a percent of total LTSS spending) was only 33.8% in 2009, with 16 states spending more than the average, 34 states spending less, and nine states decreasing spending on HCBS from 2004-2009. The authors suggest that stagnant wages for personal and home care aides and higher salaries for home health aides in institutions may challenge rebalancing efforts and suggest that Medicaid wage-pass through programs may be a strategy. Hilltop Institute: "Rebalancing Long-Term Services and Supports: Progress to Date and a Research Agenda for the Future"

Targeted Outreach to Connect People with HCBS Lowered Costs
A study of the Arkansas Community Connector Program in the July 2011 issue of Health Affairs finds that using community health workers to connect people at risk of nursing home placement with Medicaid home and community based-services (HCBS) actually reduced spending per participant by 23.8% on average.

The authors explain that some experts suggest HCBS programs may not be cost effective due to a "woodwork effect" theory of people enrolling in HCBS who wouldn't otherwise use institutional care- thus driving up costs. This study appears to contradict that theory. The three-year program used community workers to conduct targeted outreach to people in three counties at risk of nursing home placement in the near term to connect them with HCBS services. The authors compare the intervention group of 919 Medicaid recipients with a statistically matched group of 944 Medicaid recipients from five nearby counties.
While both groups experienced growth in per-participant spending during the three-year period (19.3% for study group, over 30% for comparison group), the study group's increase was tied to increased HCBS while the largest driver of the comparison group's increase was more spending on nursing home services. The Community Connector Program ultimately achieved a net savings (after paying the program costs) of $2.619 million for the Medicaid program, a return on investment of $2.92 per dollar invested in the program. *Health Affairs:* "Medicaid Savings Resulted When Community Health Workers Matched Those With Needs, To Home And Community Care" (abstract and article are free)

**Minority Elders May Have Less Access to HCBS**

A study in the July 2011 issue of *Health Affairs* uses data from the Minimum Data Set on the US nursing home population from 1999 to 2008 to analyze use of home and community-based services (HCBS). The authors explain that despite a policy shift to allow people to age in their own homes with the support of HCBS, the number of minority elders living in nursing homes actually increased from 1999 to 2008. The numbers of elderly Hispanics grew by 54.9% during this time frame, elderly Asians increased 54.1%, and elderly black residents increased 10.8%. In contrast, the number of elderly whites in nursing homes decreased by 10.2%. The increase of nursing home residents corresponded to larger total elder minority populations during the same time frame. The number of Hispanic elders increased 58.2%, Asian elders increased 64.2%, and black elders increased 16.2%, while white elders increased 6.7%.

The authors speculate that changing family structures for minority populations may have led to less availability of family-based care options. While it appears that minorities now have greater access to formal long-term care, because nursing homes are perceived as "the last resort," this improved access may actually just be "a shifting of disparities, with minorities still underrepresented in preferred sites of care." They conclude that white elders may have more choices of care and may be better able to afford community options like assisted living, and also note that when minority elders do use nursing homes, they tend to be at lower-quality facilities. *Health Affairs:* "Growth of Racial and Ethnic Minorities in US Nursing Homes Driven By Demographics and Possible Disparities in Options" (abstract is free)

**California: Paying Family Caregivers Less Expensive**

A study in the August issue of the *Gerontologist* uses 2005 Medicaid claims and In-Home Supportive Services (IHSS- California's personal care program in Medicaid) data to compare costs between Medicaid recipients with paid spousal caregivers vs. recipients with other relatives or unrelated individuals as their caregivers. The authors find: "The rates of ambulatory care-sensitive hospital admissions and Medicaid-covered nursing home placements were at least comparable among IHSS recipients' with spouse, parent, other relative, or nonrelative caregivers....In no comparison did those with spouse providers have worse outcomes than those with nonrelative providers." The authors conclude that paying spouses, parents, and other relatives (through IHSS) had no financial disadvantages and some advantages (lower average Medicaid expenditures and fewer nursing home admissions) and suggest that their findings support honoring recipient's and family member's preferences for this type of arrangement. *The Gerontologist:* "Allowing Spouses to Be Paid Personal Care Providers: Spouse Availability and Effects on Medicaid-Funded Service Use and Expenditures" (abstract is free)

**California: 33 Older and Disabled Californians who are Living in the Community**

A policy brief released by the UCLA Center for Health Policy Research highlights the experiences of 33 older and disabled Californians who are dually eligible for Medicare and Medicaid and who are receiving non-institutional long-term services and supports. One of the policy recommendations in the report is to consolidate California's many long-term care programs and provide a single entry point for participants. *UCLA CHPR: Independence at Risk: Older Californians with Disabilities Struggle to Remain at Home as Public Supports Shrink*

**California: Medicaid HCBS Waivers, Benefits, Eligibility from 2005-2008**

A report from the California Medicaid Institute at UCSF analyzes data on California's home and community-based services (HCBS) waivers from 2005-2008. The
authors explain that the growing cost of these programs for the state, as well as an expected increase in demand, suggests two questions to policymakers. The first question is the relationship between participation in an HCBS program and the use of institutional settings. The second question is whether or not participation in HCBS reduces use of ER visits, hospital stays, and total Medi-Cal spending.

The report provides a concise snapshot of California's waiver programs, including participation, cost, financial eligibility rules, and history of the program. IHSS, the state's Personal Care Service Program, paid for, on average, 21.4 hours of week in 2008, while the authors note that the national average of care provided (both paid and unpaid) is 31.4 hours a week. For Adult Day Health Care, the program served an average of 41,542 clients at a monthly cost of $879, and total annual expenditures of about $4.30 million in 2008. California's MediCal Home & Community Based Services Waivers, Benefits & Eligibility Policies, 2005-2008

Note: The authors also released a report describing how they created a database with data from Medi-Cal and Medicare on claims, assessment, and enrollment for both programs. The report explains how the authors acquired the data, as well as the contracts and data use agreements that enabled the sharing of Medi-Cal and Medicare data, and how the Institute complied with these agreements. "Studying Recipients of Long-Term Care Services and Supports: A Case Study in Assembling Medicaid and Medicare Claims and Assessment Data in California"

California HCBS: An August 2011 brief from the Scan Foundation, "Medicaid-Funded Home and Community-Based Services" provides an overview of HCBS, with a focus on California. Because the programs have evolved over time in California, they are administered by several different state agencies and consumers must meet eligibility requirements and be approved by each program individually. In addition, the authors explain that Medicaid's bias towards institutional care means that HCBS programs are more likely to be cut during lean budget years. Scan Foundation: "Medicaid-Funded Home- and Community-Based Services"

California: Overview of Demonstration Waiver
The Kaiser Commission on Medicaid and the Uninsured released an issue brief in October 2011, focused on California’s “Bridge to Reform” Medicaid Demonstration Waiver, which includes roughly $8 billion in federal Medicaid matching funding for the state. The waiver is intended to expand coverage for low-income uninsured adults, improve the county-based safety-net, and allows the state to enroll elderly and disabled Medicaid beneficiaries into managed care. Kaiser Commission on Medicaid and the Uninsured: “California’s Bridge to Reform Medicaid Demonstration Waiver"

California and Texas Medicaid Waivers Compared
A December 2011 fact sheet from the Kaiser Commission on Medicaid and the Uninsured compares the two Medicaid Demonstration Waivers approved for California and Texas. Both waivers include billions in matching federal funds and are scheduled to last five years. Kaiser Commission on Medicaid and the Uninsured: “California and Texas: Section 1115 Medicaid Demonstration Waivers Compared”

Georgia: Profiles of State's Medicaid Program
An article in the Atlanta Journal Constitution focused on the role of Medicaid in paying for long-term care in Georgia. Medicaid currently pays for almost 28,000 Georgians living in nursing homes, and while the state receives 2,200 Medicaid applications a month, more than 40% are denied. Similar to other states around the nation, Georgia has shifted more money to home and community-based services through its Community Care Services Program, which currently serves 12,000 people, however, there are 1,707 people on the waiting list for the program. A mother and daughter are profiled in the story, while the mother was initially declined for Medicaid because of her pension ($3,000 a month from the Dept. of Defense), using a qualified income trust, she was approved for Medicaid, with almost her entire pension check going to the nursing home and Medicaid paying for the rest. Atlantic Journal Constitution: "Seniors turn to Medicaid for long-term care"

Ohio: Evolving Medicaid Long-Term Care Programs
A report on Ohio's long-term care system used 16 years of program data to examine how the state's system has evolved. PASSPORT, one of Ohio's Medicaid waiver programs highlighted in the report, allows consumers to receive in-home services within the community instead of institutional care. The cost of PASSPORT per month is $1,067, while nursing homes are $4,281, and PACE is $2,643. The authors note that the average monthly caseload for PASSPORT has grown from 15,000 in 1995 to 30,000 in 2010, placing Ohio in third place for
largest waivers for older adults, behind Washington and Texas. Policy recommendations include increasing prevention and self-sufficiency (about 49% of the 146,000 older adults with severe disability rely on Medicaid), using technology, increasing effectiveness and efficiency in service delivery, better support for the growing number of family caregivers and better data collection to improve policymaking. A family caregiver provided her perspective of the PASSPORT program in a follow-up newspaper column and explained how the program supports her and her brother and allows her mother to age in her home.

Cincinnati.com: "More ailing, aging loved ones are being cared for by relatives"

Ohio: Increases for PASSPORT Medicaid Waiver
The Toledo Blade profiled Ohio's response to providing long-term care, especially through its PASSPORT (Pre-Admission Screening System Providing Options and Resources Today) Medicaid Waiver. The state's most recent budget provides a $55.6 million increase for PASSPORT through 2013, resulting in 4,800 more Ohioans being able to access home and community-based services through the program at about one-third of the cost of nursing home care. The state will also spend $166 million more in total spending on Medicaid long-term care services and supports in addition to the increased money dedicated for PASSPORT.

Toledo Blade: "More ailing, aging loved ones are being cared for by relatives"

State Olmstead Violations and Other Legal Developments

The Supreme Court ruled in the 1999 Olmstead v. L.C. decision that states must serve the elderly and disabled in the most integrated settings possible. Medicaid HCBS are one of the primary channels for states to meet the requirements of the Americans with Disabilities Act (ADA). When changes or reductions are made to HCBS, or other programs that enable living in the community, advocates often sue to prevent the cuts. The US Department of Justice (DOJ) also works to enforce the ADA. In June 2011, the DOJ released a Questions and Answers resource on the ADA Mandate and Olmstead enforcement.78

California: A report by Californians for Olmstead focuses on the state's current adherence to Olmstead and future steps for advocates. The report begins with a survey of the California disability community, who cited challenges and successes with the current Olmstead plan, including little to no progress in implementing recommendations, and policymaker's acknowledgment of the effectiveness of the IHSS program while also cutting the budget for the program. Progress on deinstitutionalization in the Departments of Developmental Disabilities and Rehabilitation were both applauded.

The state of California made approximately $15 billion in cuts to health care and social services since FY 2008/09, resulting in an additional $15 billion loss in matching federal dollars. Within the context of budget cuts, the passage of the Affordable Care Act, and shifts to managed care, the author recommends three priorities, including promoting consumer direction, preserving the non-profit, community-based safety net provider network, and focusing on fiscal incentives and advocating for them to be aligned to support HCBS. The DOJ filed statements of interest in a lawsuit against the state for California’s proposed elimination of Adult Day Health Care.80

Delaware: In July 2011, the DOJ filed a complaint and settlement agreement with the state focused on whether people with mental illness are being served in the most integrated settings possible. The complaint/agreement also addressed conditions at the Delaware Psychiatric Center. Under the agreement, the state pledged to create a “comprehensive community crisis system to serve as the front door to the state’s mental health system,” offer at least 650 housing vouchers to allow people to obtain stable, integrated housing, and offer employment (1,100

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78US Department of Justice, Civil Rights Division. Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II on Enforcement of the Integration


people) rehabilitation (1,100 people), and family/peer support services (1,000 people).\textsuperscript{81}

**Illinois** An August 2011 article in the *Chicago Tribune* explains that the state was close to settling a class action lawsuit and would need to offer subsidized apartments to up to 20,000 nursing home residents who were interested and able to move out of nursing home care. The plan would call for 1,100 nursing home residents to move out of nursing homes and into apartments and group homes during a 30-month period. People who move out would receive rental assistance of about $700 per month as well as $4,000 in transition funds (as a voucher) to furnish their apartments. *Chicago Tribune*: “State may end reliance on nursing homes for disabled adults”

**Kansas:** The head of the Olmstead enforcement team visited Kansas to discuss Olmstead with the Topeka Human Relations Commission. In addition to long waiting lists and Kansas not having an Olmstead plan, advocates expressed concern that a potential plan to reduce Kansas Medicaid spending by $200 million will likely reduce or weaken HCBS.\textsuperscript{82}

**Missouri:** The DOJ filed a statement of interest in a case against Missouri in which the state was eventually ordered to provide Medicaid-funded incontinence supplies for people who need them in order to prevent being placed in nursing home facilities.\textsuperscript{83}

**Mississippi:** The DOJ notified the state that it was in violation of the Americans with Disabilities Act in December, 2011. In a letter to the Governor, Thomas Perez, an Assistant Attorney General, noted that Mississippi had the most “institution-reliant system in the United States” for providing services to people with disabilities and noted the state spends more money proportionately on institutional care and less on community services than any other state.\textsuperscript{84}

**New Hampshire:** The DOJ notified the state in April 2011 that it failed to provide services to individuals with mental illness in the most integrated settings possible, and that a reduction in community capacity has led to unnecessary institutionalization and a greater likelihood that some people could end up in the state corrections system and county jails.\textsuperscript{85}

**New York:** The New York state government neared closure on a case related to the residential options provided to mentally ill residents. According to the *New York Times*, the case was first filed in 2006 and focuses on whether or not the state offers sufficient options for people who are capable of living independently within the community. Under the settlement, which is expected to impact over 1,000 people, the state agreed to reform the assessment process for determining if a person can live independently and will hire independent contractors to conduct the assessments. The settlement creates a three-year deadline for the state to move qualified people into the community and commits the state to developing 200 new units of supportive housing.\textsuperscript{86}

**North Carolina:** The DOJ issued a Finding Letter in July 2011, informing the state that its administration of its mental health system causes unnecessary institutionalization of individuals with mental illness in segregated facilities known as adult care homes. The DOJ recommended the state developing scattered site supported housing and the provision of community-based support services.\textsuperscript{87}

**Pennsylvania:** In May 2011, a court approved a settlement agreement between the state and a group of plaintiffs that sued over the state’s failure to provide sufficient community-based services for individuals with developmental disabilities. The agreement requires the


\textsuperscript{83} Hiltibran v. Levy, Case No. 10-4185-CV-C-NK. Retrieved from: [http://www.ada.gov/olmstead/olmstead_cases_list2.htm#uspar](http://www.ada.gov/olmstead/olmstead_cases_list2.htm#uspar)

\textsuperscript{84} Perez, Thomas (2011, December 22). Letter to the Honorable Haley R. Barbour, Governor of the state of Mississippi. Retrieved from:


state to provide 325 community placements for residents currently living in intermediate care facilities.\textsuperscript{88}

**Tennessee:** Several people with disabilities are suing the state for Olmstead violations after a cap was implemented that limited one-on-one nursing services to 12 hours a day, while personal assistance services are capped at 215 hours a month (about 7 hours a day).\textsuperscript{89}

**Texas:** The DOJ filed several documents in a lawsuit against Texas for violations of the Americans with Disabilities Act related to segregation of individuals with developmental disabilities in nursing homes.\textsuperscript{90}

**Virginia:** A February 2011 letter to the state from the Department of Justice found that Virginia was in violation of the ADA mandate in its operation of its developmental disabilities services through the use of large institutions, the use of a waitlist with 3,000 individuals, and a lack of sufficient community-based services.\textsuperscript{91}

**Washington, DC:** The *Washington Post* reported that a settlement in Washington, DC, will pave the way to end court oversight of its services for the mentally ill.\textsuperscript{92} A case was originally filed in 1974 to force the city to provide alternatives to institutionalization, while some progress was made, the city's mental health department was placed into receivership in 1997. The city also agreed to build 300 additional housing units and add $3.5 million to the budget to fund improvements. The DOJ filed an amicus brief in October, 2011 for a lawsuit against the District of Columbia, alleging violations of the Americans with Disabilities Act.\textsuperscript{93}

**Washington State** In December 2011, the Ninth Circuit Court of Appeals granted injunctive relief to plaintiffs who sued the state after the state’s Department of Social and Health Services moved to reduce the amount of in-home personal care service hours by an average of 10% in the state’s Medicaid plan starting in January 2011.\textsuperscript{94}

**Wisconsin's** budget included a cap on its Family Care Program that is estimated to save $100 million over the course of two years, but advocates have suggested the cap may lead to Olmstead violations. An Op-Ed about the cuts explains that when Family Care was implemented, counties "turned over" their funding to the state with the understanding that it would provide services through Family Care. The authors suggested that the state was going back on that agreement but keeping the funding. In a letter asking CMS to block the changes, advocates noted that as part of the original design, every eligible person was required to have entitlement to Family Care within 36 months of the waiver being implemented in their county.

The *Journal Sentinel* reported that Wisconsin Governor Scott Walker announced on December 28, 2011 that the state would remove enrollment caps on the Family Care Program in Wisconsin. According to the *Journal Sentinel*, Governor Walker made no mention of an order from CMS sent two weeks earlier that required the state to lift the cap. Family Care is currently available in 57 of the state's 72 counties and Walker's plan (which would require approval of the legislature) would expand access to the remaining 15 counties. There are currently 43,000 people in the program, with 6,600 people on a wait list (an increase of 853 since the cap), though a deputy secretary for the Department of Health Services said not all people on the waiting list are eligible for Family Care.\textsuperscript{95}

\textsuperscript{90} United States Supplemental Statement of Interest in opposition to Defendants' Partial Motion to Dismiss Plaintiffs' Amended Complaint (2011, November 30). Steward et. al. v. Perry et. al. 5:10-CV-1025. Retrieved from: http://www.ada.gov/olmstead/olmstead_cases_list2.htm#steward  
Medicare

There were several notable developments affecting Medicare in 2011. In August, HHS reported that over 17 million beneficiaries with Original Medicare had received one or more free preventive services, and that over one million Americans had also visited their doctor for the new Annual Wellness visit.\(^\text{96}\) In addition, CMS announced that it would pay for the cost of annual depression screenings.\(^\text{97}\) A study released in July 2011, by Harvard Medical School and Brigham and Women’s Hospital found that the Medicare Part D drug benefit led to an average reduction of $1,200 in costs annually for emergency room visits and nursing home care for beneficiaries who had a limited prescription benefit prior to Medicare Part D being implemented. In contrast, a Spanish study released in July 2011 found that a universal exemption from copayments for prescription medications for retired people increased the consumption of medications by 9.5%, total expenditures by 15.2%, and insurance costs by 47.5%, but without a corresponding reduction in the rate of hospitalizations.

Several proposals suggested turning Medicare into a voucher/premium support program, however, they did not gain traction.\(^\text{98}\) Kaiser Health News noted that more than half of the deficit reduction proposals in 2010 and 2011 included provisions to increase costs on wealthy Medicare beneficiaries.\(^\text{99}\) However, only five percent of Medicare beneficiaries have incomes greater than $80,000.\(^\text{100}\)

A class action lawsuit was announced against CMS in November 2011, based on issues arising from outpatient vs. inpatient status in hospital stays and how this can affect the hospital bills for people with Medicare.\(^\text{101}\) The Independent Payment Advisory Board (IPAB) was created in the Affordable Care Act, and starting in 2015, the board will be charged with recommending cuts to Congress if Medicare costs are growing too quickly. Congress will have to either approve the cuts or find an equivalent amount of savings elsewhere. The board has been criticized by some for having too much power or for “rationing care.”\(^\text{102}\) The federal government continued an aggressive campaign against Medicare fraud, and the Obama administration announced that it had recovered $5.6 billion in fraudulent payments in FY 2011, a 167% increase from 2008.\(^\text{103}\)
Table 3: Research Briefs Focus On Medicare

The Scan Foundation released a number of data briefs focused on Medicare recipients, where they live, and their utilization of services.

**Data Brief No. 16** focuses on the rebalancing that states have engaged in with their LTSS systems, resulting in 58% of older Americans who need assistance with two or more ADL's living in the community or residential care settings while 38% reside in nursing homes.

**Data Brief No. 17** addresses how Medicare spending varies for seniors with moderate or severe disabilities varies depending on the setting in which seniors live. Medicare spent $14,594 per capita on nursing home residents, $14,001 on residential care residents, and $18,307 per capita on community residents in 2006.

**Data Brief No. 18** compares expenditures on seniors with moderate or severe disabilities to seniors without disabilities and finds that seniors with disabilities use more services across all groups, with community-residing seniors having higher utilization of inpatient care.

**Data Brief No. 19** analyzes spending for seniors with moderate or severe disabilities (needing assistance with two or more ADL's) and finds that 21% of seniors who live in community settings had hospital stays as compared to 12% for these seniors who reside in nursing homes.

**Data Brief 20** focuses on the prevalence of functional impairment among seniors by the number of chronic conditions.

**Data Brief 21** compares the proportion of dually eligible seniors with both chronic conditions and functional impairment to seniors who are only eligible for Medicare.

**Data Brief 22** compares Medicare spending on seniors with chronic conditions and functional impairments to seniors with only chronic conditions.

**Data Brief 23** describes the distribution of seniors with chronic conditions and functional impairment between Medicare's spending quintiles.

**Data Brief No. 24** analyzes spending on seniors and is broken down by the presence of chronic conditions and functional impairment.

**Data Brief No. 25** compares health service utilization for seniors with both chronic conditions and functional impairments and compares them to seniors with only chronic conditions.
Lawsuit Focuses on Outpatient vs. Inpatient Status
The Hartford Courant reported in November 2011 that the Center for Medicare Advocacy planned to file a lawsuit against the federal government based on the issues that arise from Medicare patient stays being designated as outpatient or observational status as compared to in-patient status. An attorney for the organization explained that the difference in how a person is designated while they are at the hospital will impact whether or not a post-hospital stay at a nursing home is paid for by Medicare. The National Senior Citizen Law Center is co-counsel in the suit and the article features an interview with a Connecticut woman whose husband was designated "out-patient" status despite being in the hospital for five days.

Hartford Courant: "Advocates For Medicare Patients To File Lawsuit Against Federal Government"

Financial Challenges for Medicare Beneficiaries
The Kaiser Family Foundation released three policy briefs that analyze the income, assets, and out-of-pocket expenses for current and future Medicare beneficiaries.

"Health Care on a Budget," finds that Medicare households spent 14.9% of their household budgets on health expenses in 2009, significantly higher than the 4.8% spent by non-Medicare households. Medicare households whose income places them just above the poverty level spend a greater share of their household budgets on health care than those below the poverty level and highest income households. For example, Medicare households below the poverty level who have members that are also covered by Medicaid spent about 85% lower on out-of-pocket expenses than Medicare households below the poverty level without Medicaid ($493 vs. $3,323).

Medicare households spent 14.9% of their household budgets on health expenses in 2009, significantly higher than the 4.8% spent by non-Medicare households.

"How Much Skin in the Game is Enough?" examines Medicare beneficiaries and their share of income going to pay for health care from 1997 to 2006. Out-of-pocket spending rose from 11.9% in 1997 to 16.2% in 2006. One in four Medicare beneficiaries spent 30% or more of their income on health expenses in 2006, and 69% of Medicare beneficiaries spent more than ten percent of their income on health care costs. Average out-of-pocket expenses per Medicare beneficiary was $4,241 in 2006. The authors explain that if previous trends continue, median out-of-pocket spending will reach 26% of income by 2020.

"Projecting Income and Assets" addresses the income of Medicare beneficiaries and finds that half of Medicare beneficiaries had incomes of $21,000 or less in 2010 and less than five percent of beneficiaries have incomes of $83,000 or more. Similar to non-Medicare beneficiaries, there are also wealth and income disparities, with higher asset and income levels for white beneficiaries than black and Hispanic beneficiaries. When averaged together (including those without assets), Medicare beneficiaries have almost $360,000 in assets ($40,228 in retirement accounts, $101,834 in home equity, $216,436 in financial assets). However, half of Medicare beneficiaries have a little over $92,000 in total assets ($2,095 in retirement accounts, $60,025 in home equity, and less than $30,287 in financial assets). The authors conclude that asset gaps will continue, with white Medicare beneficiaries projected to have $471,353 in savings by 2030 while black beneficiaries will have $101,148 and Hispanics will have $143,639.

Out-of-Pocket Spending on Health Care
A February 2011 report from AARP’s Public Policy Institute analyzed 2006 Medicare data and found that beneficiaries spent a median of $3,103 a year on health care in 2006. Ten percent of the population (more than four million people) spent more than $8,300 per year. The authors note that out-of-pocket spending was much higher for people in poor health condition (22% of income) as compared to people in excellent health (15% of income).

AARP PPI: "Medicare Beneficiaries’ Out-of-Pocket Spending for Health Care"

16 Medicare Beneficiaries, Close To Financial Edge
A report from the Kaiser Foundation profiled 16 Medicare beneficiaries and their financial situations. Half of the individuals/couples profiled have incomes below twice the poverty level (under $22,000 for an individual), which is the same proportion of the total Medicare population. The people interviewed use a variety of strategies to make ends meet with limited or fixed incomes, including incurring credit card debt for regular expenses, prematurely dipping into nest eggs, and relying on money from adult children. Several themes emerged, including barely making ends meet, Medicare playing an important role in ensuring access to health care yet people still postponing medical care, especially if there are out-of-pocket costs, and debt,
minimal savings, and concerns about the future as the norm for most of the couples profiled. The Agency for Healthcare Research and Quality (AHRQ) released data in June that roughly one of every six Americans aged 18 to 64 report using more than 10% of their total family income to pay for health insurance premiums and out-of-pocket medical expenses in 2007.

Kaiser "Living Close to the Edge: Financial Challenges and Tradeoffs for People on Medicare"

Kaiser Video "Making Ends Meet: The Medicare Generation"

Kaiser Briefing "The Role of Medicare and Beneficiaries in the Deficit-Reduction Debate"

AHRQ "Who Paid More Than 10 Percent of Their Family Income for Medical Expenses?"

MedPAC Recommends Copay for Home Health Care

In January 2011, members of the Medicare Payment Advisory Commission (MedPAC) recommended to Congress creating a copay for home health care services provided through Medicare. Members of the Commission agreed on a copayment of $150 for each 60-day home care treatment period or episode. The chairman of MedPAC, Glenn Hackbarth, explained that evidence suggest copays have the potential to reduce health care use. Staff members from MedPac suggested that there was a 17.7% profit margin in 2009 for free-standing home health agencies. In President Obama’s proposed budget for FY 2013, he proposed implementing a co-pay for home health care.

Commonwealth Fund: "Washington Health Policy Week in Review MedPAC Study Finds Variations in Use of Post-Acute Care in Medicare"

New Yorker: "The Cost Conundrum-What a Texas town can teach us about health care"

Costs during Last 6 Months of Life Are Driven by Patient Variables, Not Geography

A study in the February 2011 issue of The Annals of Internal Medicine found that patient characteristics, including functional ability, severity of illness, and presence of family support accounted for 10% of variation in Medicare costs as compared to 5% of variation that was tied to regional factors, like the number of hospital beds. Catherine Sarkisian, MD, an Associate Professor in the Division of Geriatrics at UCLA and the senior author on the study explained that the presence of a caregiver may help patients avoid undesired hospital stays. Amy Kelley, MD, the lead author, explained that the findings suggest: “Health care reform will have the greatest impact on reducing costs if we focus on providing well-coordinated, high-quality care for the most complicated patients and their family caregivers.”

The Annals of Internal Medicine: “Determinants of Medical Expenditures in the Last 6 Months of Life”

Older Americans Act Programs for Family Caregivers

November 2011 marked the 11th anniversary of the National Family Caregiver Support Program. November is also National Family Caregiver’s month, and to commemorate the month, FCA invited guest bloggers to write for the “30 Days of Caregiving” blog series, which culminated on the last day with "Caregivers Share Their Wisdom" with perspectives from family caregivers who participate in FCA’s online caregiver support group. While several bills were introduced, the Older Americans Act has yet to be re-authorized.

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**Brief Provides Primer on the Older Americans Act**

The National Health Policy Forum released a guide on the Older Americans Act. The brief explains the programs within the seven titles of the act (of which six are run through the Administration on Aging), the history of the act, and how funding is allocated. **National Health Policy Forum: "Older Americans Act of 1965: Programs and Funding" (Guide updated in 2012)**

**Budget Reductions Limit Capacity of AAA’s**

The National Association of Area Agencies on Aging (n4a) released its 2010 Survey of Area Agencies on Aging (AAA’s) in July 2011. Scripps Gerontology Center conducted the survey which had a 71% response rate from the 629 AAA’s. The report provides a broad overview of the many services provided through AAA’s, however, budget shortfalls also constrained capacity, with 60.5% of AAA’s reporting cutting budgets in all or some departments. These reductions led to 52.7% reporting increase caseloads, 50.2% eliminating or reducing salary increases, 24.2% converting full-time positions to part-time positions, and 23.3% using lay-offs. In addition, 58.7% instituted waiting lists for new clients and 37.4% restricted the number of clients served based on budget levels. Despite funding cuts, 82% of AAA’s report involvement in implementation of an evidence-based program, 66.1% reported establishing coalitions with other entities to promote coordination across service sectors and planning departments, and 60% report the existence of a program to divert consumers from institutional care. **N4a "Area Agencies on Aging: Advancing Health and Long-Term Services and Supports"**

"The beauty of the Older Americans Act is that it allows you to retain your dignity, health and independence with just a little bit of support.”

**Older Americans Act Hearing**

On May 26, 2011, the Senate Special Committee on Aging hosted a hearing about the reauthorization of the Older Americans Act. Former first lady Rosalynn Carter testified about her organization’s report: "Averting the Caregiving Crisis, Why we Must Act Now." Assistant Secretary Kathy Greenlee explained the difficulties faced by "sandwich caregivers" and the important role of programs funded by the Older Americans Act in allowing people to "age in place." Elizabeth Marshall, a former mayor of York, Pennsylvania testified about the services she receives through her local Area Agency on Aging, including Meals on Wheels. She explained, "The beauty of the Older Americans Act is that it allows you to retain your dignity, health and independence with just a little bit of support. It forms the critical glue that holds together all the other supports I have: my adult children, my friends and neighbors, and my own determination to age in place." **Senate Special Committee on Aging "Meals, Rides, and Caregivers: What Makes the Older Americans Act so Vital to America's Seniors"**

**Witnesses Heard "At Your Age" When She Applied for Employment**

At a congressional hearing, several witnesses discussed the importance of programs funded under the Older Americans Act. Gail Ruggles, a witness from Vermont, gave a stirring presentation about the real-life impact of the Senior Community Services Employment Program (SCSEP) in keeping her out of poverty, explaining, "I really don't like public aid offices, the staring, the plastic chairs, the guarded looks from the interviewers, and the sense of having to defend myself and my life's failings and ask for a handout... But the office of Vermont Associates was a different kind of aid station." Ruggles explained that participating in SCSEP increased her self-esteem, employability, skills, and led to a full-time job. **Hearing: "The Recession and Older Americans: Where Do We Go from Here?"**

**One Way Campaign Asks Congress to Reauthorize Older Americans Act**

The National Council on Aging's (NCOA) interactive One Away campaign has gathered over 4,600 stories from the 13 million seniors with incomes of $22,000 or less who are "one crisis away" from poverty. NCOA is asking senators and representatives to sign a pledge to protect and strengthen the Older Americans Act. A 2010 GAO report on Title III programs funded by the Older Americans Act found that 69% of states reported reduced state funding in FY 2010 while 19% of agencies reported being "generally or very unable to serve all seniors who requested home delivered meals" and 27% reported being "generally or very unable" to meet all requests for respite care. **NCOA "One Away" Campaign**

**GAO: OLDER AMERICANS ACT Preliminary Observations on Services Requested by Seniors and Challenges in Providing Assistance**

**Lifespan Respite Care Program Reauthorization**

The Administration on Aging asked for input concerning the reauthorization of the Lifespan Respite Care Program.
(LRCP) in 2011. 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. In addition, Vice President Biden's Caregiver Initiative, which would have provided additional funding to provide an estimated additional three million hours of respite, was not passed because Congress passed a Continuing Resolution bill instead of passing the Senate Appropriations Bill funding the Departments of Health, Labor, and Human Services.

Congressional Research Service: "Family Caregiving to the Older Population: Legislation Enacted in the 109th Congress and Proposals in the 110th Congress" (Jan, 2008)

Vice-President Biden's "Caregiving Initiative"

2011 Resources on Respite from ARCH National Respite Network and Resource Center:

- National Respite Guidelines, 2011
- Participant-Directed Respite Guidebook, 2011
- 2011 Compendium of State Respite Coalition Fact Sheets
- Home and Community-Based 1915(c) Medicaid Waivers for Respite Support: State-by-State Tables, 2011
- State Funding Streams for Respite Across the Lifespan, 2011

Research on Family Caregivers

A wide range of research focused on caregivers was released in 2011. While there was excellent research conducted on the financial, psychological, emotional, and health risks of being a family caregiver, action based on this research seems slow to materialize, if at all. A large policy disconnect exists between research that demonstrates the importance of identifying, assessing, and supporting caregivers, and the current status quo of expecting families to take this role on without assistance in the many issues that they will encounter in their caregiving journeys.

72% of Employed Caregivers Are Caring For a Parent

Gallup released data from surveys of employed caregivers, with three in-depth articles. The first article focuses on demographics of caregivers and a trend that the less income and education an American has, the more likely they are to be a caregiver. Twenty-one percent of Americans who make $36,000 or less, report that they are caregivers, while only 15% of high income ($90,000+) employees report serving as caregivers. The authors speculate that higher-income Americans may be able to pay for professional care, or potentially that higher income/educated Americans tend to be younger.

Gallup Part One: More Than One in Six American Workers Also Act as Caregivers

The second article highlights data on caregiving and employment and finds that while 71% of caregivers report that their employer is aware of their caregiving role, only about a quarter of employees have access to employer programs that would support them, for example support groups, ask-a-nurse services, financial/legal advisors, and assisted living counselors. The 17% of the American full-time workforce are caregivers missed a combined 126, 222, 624 workdays each year, at an estimated cost to the economy of $25.2 billion in lost productivity.

Gallup Part Two: Caregiving Costs U.S. Economy $25.2 Billion in Lost Productivity

The third article provides data on the amount of time and types of caregiving activities that people perform. In a survey of 2,805 employed caregivers, 72% are caring for a parent and 55% reported providing care for three years or more. Caregivers assisted with general day-to-day tasks on an average of 13 days a month, while providing personal assistance with activities like toileting, dressing, eating and bathing on an average of six days a month. The majority of caregivers (64%), report that the care recipient does not live with them, however, of those who don't live with the care recipient, 66% live within ten miles of the care recipient. Caregivers report that on
average, they spend five hours a day providing companionship or supervising their loved ones and thirteen hours a month on navigating health care, coordinating disease visits, and managing financial manners for their loved one.

Gallup Part Three: Most Caregivers Look After Elderly Parent; Invest a Lot of Time

Caregivers Provided $450 Billion in "Free" Care
AARP’s Public Policy Instituted released its 2011 update of “Valuing the Invaluable: The Growing Contributions and Costs of Family Caregiving.” The authors find that the nation's 42.1 million family caregivers provided an estimated $450 billion in care in 2009, a $75 billion increase from 2007. The authors explain that the "average" U.S. caregivers is a woman, 49 years old, who works outside the home while also providing almost 20 hours of care to her mother for almost five years. The majority of caregivers are female (65%), and more than 80% are caring for a relative or friend who is age 50 or older. The $450 billion amount was calculated based on an hourly wage of $11.16 an hour and 18.4 hours of care provided per week. Family caregivers are identified as the "hidden patients" who need support and care to address the many negative health, psychological, and financial challenges brought on by caregiving. While the field of family caregiving has made progress, the authors explain that a number of inexpensive policy changes could be implemented to better support the nation's caregivers. The report includes data on the amount of "free" care provided in each state. AARP PPI: "Valuing the Invaluable"

Middle-Aged California Caregivers Face Most Health Risks
A research brief on California family caregivers finds that middle-aged caregivers are at greater health risks because of caregiving as compared to older caregivers. One-third of California caregivers live with the care recipients, and these caregivers provide 36 hours of care per week which the authors note is almost a full-time job. Only 7.4% of caregivers report receiving compensation for the care they provide, and 20% report that they spent over $250 of their own money on caregiving in the past month.

Older caregivers are more likely to care for a spouse or partner (29.8%), live with the care recipient (45.2%), provide more hours of weekly care (32.2 hours), and care for longer durations (61.8 months). Middle-aged caregivers are more likely to binge drink (25.2%), smoke (15.9%), and/or be obese (30.1%) than both non-caregivers of the same age and older caregivers. Middle-aged caregivers exhibited poorer health status (9.8% with diabetes, 6.8% have heart disease, 34.3% have high blood pressure), and 58.1% report that they have a full-time job in addition to caregiving.

The authors note that existing supports for California caregivers have faced cuts (IHSS) or elimination (Adult Day Health Care). In addition, California announced in September 2011 that it was abandoning a plan to add 1,000 additional slots for the Multi-Senior Service Plan (MSSP) as part of its transition to eliminate Adult Day Health Care. A state representative explained that these slots were dropped because there are already 1,600 people waiting long periods of time for MSSP. UCLA Center for Health Policy Research: “Stressed and Strapped: Caregivers in California

LGBT Seniors and Caregivers
Caring and Aging with Pride, a project based at the University of Washington School of Social Work, recently released a report which used data from the caregiver module in the BRFSS survey in Washington State as well as interviews with LGBT older adults from across the nation that were coordinated through 11 community-based agencies. The authors estimate that 2% (more than two million) of adults age 50 and older currently self-identify as lesbian, gay or bisexual, and this number will likely double by 2030. In contrast to the general population of caregivers, LGBT older adults had high rates of caregiving for both men (26%) and women (30%). While the authors focus on the challenges faced by LGBT seniors, they also highlight their societal contributions: "Forty-one percent of transgender older adults, 41% of bisexual men, 34% of gay men, and 6% of lesbian and bisexual women participants have served in the military." Policy recommendations include targeting social and health programs for LGBT older adults within programs funded by the Older Americans Act; ensuring economic security through maintaining entitlement programs and extending benefits to same-sex partners; and amending the FMLA for same-sex partners. Caring and Aging with Pride: "The Aging and Health Report Disparities and Resilience among Lesbian, Gay, Bisexual, and Transgender Older Adults"

30 Days of Caregiving Blog from SAGE: "Day 12: Caregiving in the LGBT Community"

Focus on Youth Family Caregivers

ASA Aging's September/October 2011 issue of Aging Today focuses on the American Association of Caregiving Youth (AACY) that was founded in 1998 to identify and support young caregivers in the U.S. The group was founded by Connie Siskowski, a caregiver for her grandfather when she was 13 years old. While completing her doctorate, Siskowski studied the prevalence of caregiving at a school district in Palm Beach, FL, and found that more than 1/3 of high-school age caregivers had issues with missing school and not doing homework because of caregiving duties. A 2005 study by the National Alliance on Caregiving found that there are 1.3 to 1.4 million children (ranging in age from 10 to 20) serving as caregivers, while a 2006 report by the Bill and Melinda Gates Foundation suggested that 22% of high school dropouts leave to provide care for a family member. AACY now has 395 active students and works with eight middle schools, with an overarching role of identifying students, assisting them with skill-building, and providing support. Siskowski suggests that one unforeseen consequence of aging in place is that youth caregivers may be relied on more heavily to assist grandparents who may have otherwise been in a nursing home. Aging Today: "Shining A Light on Young Caregivers"

Research on Caregiver Roles and Decision-Making

Pathways of Adult Child Caregiver's Roles
A dissertation by Dr. Amanda E. Matzek, released in June 2011, examined pathways of adult child caregiver's roles and their relation to the psychological and physical health of the caregivers. The author analyzes data on 1,300 adult child caregivers (from the Health and Retirement study) and finds strong evidence for a 4-class model of caregivers' role pathways.

The four pathways are:
1) Married, Working Caregivers (22.5%);
2) Married, Retired Caregivers with Co-Residing Child (12.5%);
3) Married, Retired Caregivers (30.5%); and
4) Not Married, Retired Caregivers (34.6%).

Matzek finds that caregiver's experiences are different based on their role pathways: "For example, using descriptive findings, Married, Working Caregivers (pathway I) often reported the most optimal psychological and physical health outcomes followed by Married, Retired Caregivers (pathway III), Married, Retired Caregivers with Co-Residing Child (pathway II), and Not Married, Retired Caregivers (pathway IV).

Based on regression findings, Married, Working Caregivers (pathway I) reported less problematic changes in psychological and subjective physical health and more problematic changes in blood pressure compared to one of the caregiver pathways."

Dr. Matzek: "The Impact of Family and Non-Family Roles on Caregiver Health Over Time"

Will You Still Want Me Tomorrow? The Dynamics of Families' LTC Arrangements
A working paper from the Human Capital and Economic Opportunity Working Group at the University of Chicago uses data from 1995-2004 from the Oldest Old Survey to analyze family's long-term care decisions. The authors model three dimensions of care arrangements: the use of each potential care arrangement, the selection of the primary care arrangement, and hours spent in each care arrangement. Their models also distinguish between modes of care, including care provided by a spouse, an adult child or child in law, formal home health care, and institutional care. They find that as the weekly cost of full-time formal home health care increases by $100, the predicted probability of receiving this care decreases by five percentage points and the probability of this type of care being the primary care arrangement decreases by 3.3 percentage points. State Medicaid income limits also were related to care arrangements, for each $1,000 increase in the annual income limit facing unmarried individuals, there was a 4.3 percentage point increase in a lone elder relying on formal home health care (and predicted hours increased 5.7 hours per week), and a 2.1 percentage point increase in relying on institutional care.

HUMCAP: "Will You Still Want Me Tomorrow? The Dynamics of Families' Long-Term Care Arrangements"

Making Caregiving Decisions After Divorce
Several professors at the University of Missouri are researching the effects of divorce on decision making around caregiving. Dr. Teresa Cooney and Dr. Christine Proulx are co-investigators on an exploratory study that will look at women who are caregivers for their ex-husbands and the unique challenges these women face.

Dr. Lawrence Ganong is studying decision-making related to divorce, remarriage, and care for older relatives. In a study with Dr. Marilyn Coleman, study participants were presented with hypothetical caregiving scenarios, and while the majority of participants said biological factors are relevant, "they do not automatically require adult children to help older relatives." Relationship quality, a history of mutual assistance, and the availability of resources all influence caregiving decisions.

Press Release: "Relationships More Important than Genetic Ties When Deciding Who Cares for Aging Family Members, MU Researchers Say"
"Caregiving for an Ex: The Experience of Women Providing Care for Ex-Husbands"

Caregiving Experience Different for Women vs. Men; Spouses vs. Children
A paper from Bowling Green State University examines how men, women, spouses, and children experience caregiving and how risk factors are different for these groups. Based on the results, the author suggests that agencies should tailor their services to the different types of caregivers. The authors measure negative caregiving, positive caregiving, care recipient problem behavior, caregiver involvement, and reciprocal help from care recipient. Availability of other caregivers, family conflict, support from friends or relatives, and caregiver demographics. Female and adult-child caregivers generally reported having more negative experiences than male and spouse caregivers, with wife caregivers the least likely to report positive experiences. Care recipient's problem behavior was the most important risk factor for wife caregivers having a negative experience, whereas positive experience was correlated with reciprocal help from care recipients, suggesting that caregivers need recognition and care from their care recipients.

Bowling Green State University, The Center for Family and Demographic Research: "Negative and Positive Caregiving Experiences: A Closer Look at the Intersection of Gender and Relationships."

Long Distance Caregivers Have Special Needs
A study released in May 2011, analyzes issues that are unique to long-distance caregivers (estimated at 14 million people by 2012) and the challenges that they can present to health care professional as well as family members who live locally. In the interviews with 14 distance caregivers (all of the care recipients had cancer), several common themes emerged, including a lack of feeling of control and lack of knowledge. In addition, distance caregivers are unsure about when to visit and some are constrained from traveling by young children and financial constraints. While many distance caregivers sought information online, they wanted more information from health care professionals and felt a need to stay connected by hearing regular updates. When a parent of an adult child is ill, they may withhold information out of a sense of wanting to protect their adult children. The author speculates that technology devices like Skype may help improve communication between local and long-distance caregivers, patients, and health care professionals.

Oncology Nursing Forum: "Lack of Communication and Control: Experiences of Distance Caregivers of Parents With Advanced Cancer" (article is free)

Oncology Nursing Society Podcast Interview with Lead Author Dr. Polly Mazanec

Caregiving Reduces Chance of Married Men Working, but Not Married Women
An October 2011 working paper from the Center for Retirement Research at Boston College uses data from nine waves of the Health and Retirement Survey to analyze caregiving decision making. The authors find that serving as a caregiver to elderly parents reduces a married man's chance of working by 3.2 percentage points. However, serving as a caregiver did not affect the wife's chance of working. Men's decisions to work were not affected by whether or not their wife is a caregiver. Women who are the only care provider increase their work hours by one hour per week, but women whose husband is the sole caregiver decrease their work by 1.2 hours per week. The authors conclude: "Overall, for adult children with elderly parents who are married, there is considerable joint caregiving, and this joint caregiving dampens the negative effect of caregiving on work that has been observed in other studies."

Center for Retirement Research at Boston College: "Do Couples Self-Insure? The Effect of Informal Care on a Couple's Labor Supply"

Cancer Patients and Caregivers Perceive Caregiving Differently
A February 2011 study surveyed 100 cancer patients and 100 caregivers for patients with cancer and found that the patients perceive the challenges of caregiving differently than caregivers. Caregivers were more likely than patients to report difficulty with the psychosocial aspects of caregiving and were also more likely (than patients) to report helping with logistical needs. The length of time since diagnosis, race, and age were associated with patients' expressed needs, while number of hours providing care was associated with the caregivers reporting needs.

Supportive Care in Cancer: "Psychosocial aspects of caregiving: perceptions of cancer patients and family caregivers"

Receiving Informal Caregiving Associated with Increased Disability and Depression
A July 2011 study used data on 6,454 community-dwelling older adults from the Health and Retirement study to analyze the association between disability and depression and the receipt of informal care. The authors found that while an older adult’s disability and depression did result in receiving more informal care initially, however, as the symptoms worse, support is often exhausted. In addition, receiving informal care increases disability and depression, and the authors speculate that receiving help may reduce self-appraisals.
of ability to perform ADLs, decrease functional skills, and lead to negative interactions between the older adult and their caregiver, thus reducing their motivation to regain their health.

*The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences: Does informal care attenuate the cycle of ADL/IADL disability and depressive symptoms in late life?*

**Assessment of Family Caregivers**

Interest in identifying and assessing family caregivers continued in 2011. Staff from the Texas Department of Aging and Disability Services (DADS) presented a webinar in November 2011 with FCA that focused on the implementation of a caregiver status questionnaire when individuals are placed on interest lists for HCBS as well as a caregiver assessment in it Older American Act, Title III-E programs. Assessing family caregivers was also included in one of the bills introduced to reauthorize the Older Americans Act.

**Caregiver Assessments for Doctors and their Staff**

A clinical review published in September 2011 explains the importance of caregiver assessments for doctors caring for older people. The authors explain that doctors are well-positioned to identify caregivers, but because of limited time, suggest doctors identify caregivers, briefly assess their needs, and refer to a staff member in the office with interest and training in caregiving issues. Because caregivers often don't self-identify and may be reluctant to accept support, doctors may want to suggest a trial approach, appealing to other family members, or appealing to the importance of maintaining the caregiver's health so that they can assist the patient. The review provides a model assessment which is linked to interventions. In a response to the paper, two authors who developed an assessment tool for use in hospice and palliative care, suggest that time constraints aren't necessarily as challenging as suggested. They suggest dividing the support domains for caregivers into supports to enable them to be better caregivers and into supports for people who have their own needs due to their caregiver status.

*BMJ: "Assessing and helping carers of older people" (article is free)*  
*BMJ: Replies to "Assessing and helping carers of older people"*

**Importance of Caregiver Assessment, Caregiver Needs May Depend on Disease**

The June 2011 issue of *American Family Physician* features an article about caregiving, the importance of assessment to support caregivers, and caregiving challenges specific to cancer, dementia, heart failure, and stroke. The authors cite research that demand for family caregivers is expected to rise by 85% in the next few decades and explain the importance of doctors or their staff assessing caregivers (or making a referral) to ensure caregiver health and safety while linking them with additional support services. The article provides several examples of caregiver assessments and includes research about caregiver interventions, for example, a recent meta-analysis found that psychoeducational and psychotherapeutic interventions had the most consistent effects on all outcome measures. A listing of online resources for family caregivers is provided and the authors conclude with a summary of public policy issues, including the fact that funding for the National Family Caregiver Support Program ($154 million in 2009) represents approximately one-twentieth of one percent of the value of care provided by caregivers.  

*American Family Physician "Caregiver Care" (abstract is free)*

**FCA: "Caregivers Count Too! A Toolkit to Help Practitioners Assess the Needs of Family Caregivers"**

**Family Caregivers for Older Hip-Fracture Patients Need Early Assessments**

A study in the July 2011 issue of *Journal of Advanced Nursing* examined the experience of 135 family caregivers for older patients who had hip-fractures. Data on quality of life for the caregivers was collected at one, three, six, and twelve months after discharge. While caregiver scores for role performance-related scales (bodily pain, social function, role limitations due to emotional problems or physical problems) improved, their scores for general health and mental health were "significantly lower" at 12 months as compared to one month after discharge. The authors...
explain that the health-related quality of life scores were positively related to the caregiver's perceived availability of social support. They conclude that home care nurses should develop interventions early after discharge to assess and improve family caregivers' health perception, mental health, and social support. *Journal of Advanced Nursing* "Trends in health outcomes for family caregivers of hip-fractured elders during the first 12 months after discharge." (abstract is free)

**New Caregiver Quality of Life Questionnaire**

A caregiver assessment tool was released in February, 2011 in the United Kingdom. The 40-item questionnaire measures quality of life for caregivers in eight areas, including support for caring; caring choice; caring stress; money matters; personal growth; sense of value; ability to care, and caregiver satisfaction. The tool includes a short manual for use, and a scoring mechanism to measure the caregiver's quality of life. The Princess Royal Trust for Carers and the School of Sociology and Social Policy at the University of Nottingham: "Adult Carer Quality of Life Questionnaire (AC-QoL)"

**Veterans and their Families**

The human impact of the wars in Afghanistan and Iraq continued to weigh heavily on soldiers, veterans, and their families in 2011, with estimates that up to 20% (about 400,000) of the two million soldiers who served in Iraq and Afghanistan have developed or are at risk of developing PTSD. The new caregiver support program began accepting applications from post 9-11 family caregivers in May 2011, and as of November 2011, more than 1,800 Family Caregivers were approved for the Department of Veterans Affairs' (VA) Program of Comprehensive Assistance for Family Caregivers. The average monthly stipend for caregivers is between $1,500 and $1,800, and 400 more family caregivers also received health care through the program that they didn’t previously have. The VA’s Caregiver Support Line received 25,000 phone calls and emails during its first year, and Caregiver Support Coordinators responded to over 8,000 referrals through the program. The VA will be required to report in May 2013 on the feasibility of expanding the caregiver program beyond solely 9-11 veterans, who only comprise about 10% of the veteran population.

**VA Caregivers and Veterans Profiled in Article about VA Caregiver Program**

USA Today profiled Russ Marek, a staff sergeant serving in the Army's 3rd Infantry Division, who was wounded in September 2005 in Iraq by a roadside bomb. He lost his right leg and arm, suffered a brain injury, as well as burns over 20% of his body. His mother, Rose Marek, is his principal caregiver who helps him with activities of daily living like cooking. The Mareks were approved for the VA's new Family Caregiver program that includes health insurance, a monthly stipend for the caregiver, and counseling. A quarterly visit from a VA social worker ensures that the veteran is receiving adequate care. Rose Marek explains that the program helps her and her husband with expenses that they incur. She adds: "To a young couple, it’s going to mean everything. If she has to quit work and stay home, it puts a terrible financial strain on that young couple." Family Caregiver Alliance is part of a broader effort with Easter Seals, Atlas Research, the National Alliance on Caregiving, the National Family Caregivers Association and the National Alliance for Hispanic Health, that created the training curriculum for the caregivers of this program. USA Today: “Wounded vets applaud new caregivers plan”

**VA Caregiver WebSite**

**GAO: Better Coordination Needed for Joint DOD/VA Care Coordination Program**

A GAO report and accompanying testimony addressed the Federal Recovery Coordination Program (FRCP), a program that created the training curriculum for the caregivers of this program. USA Today: “Wounded vets applaud new caregivers plan”

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that was developed to assist severely wounded, ill, and injured service members, veterans, and their families. The program is intended for individuals suffering from traumatic brain injuries, amputations, burns, spinal cord injuries, visual impairment, and post-traumatic stress disorder. The program began enrollment in January 2008, and as of May 2011, the program had served 1,665 participants. The report cited challenges with the program, including difficulty identifying eligible individuals, challenges with follow-up on referrals, staffing needs, questions about appropriate caseload sizes, and difficulty in deciding where to place staff. GAO: “Federal Recovery Coordination Program: Enrollment, Staffing, and Care Coordination Pose Significant Challenges”

**Battlefield Brain Injuries Discussed at Hearing**

Traumatic Brain Injury (TBI) is considered the "signature" wound of the Iraq and Afghanistan wars, and at a hearing on March 15, 2011, Army Surgeon General Lt. Eric Schoomaker answered questions about diagnosis of TBI. Schoomaker explained that the standard tool used to measure TBI on the battlefield (Automated Neuropsychological Assessment Metrics- ANAM) fails to identify between 25 and 33 percent of soldiers who have been concussed while including 50% of soldiers who are not concussed. Schoomaker explained that the army is conducting an evaluation between ANAM and another tool, the Immediate Post-Concussion Assessment and Cognitive Testing (ImPact), a tool also used by the National Football League.

Vice Admiral Adam Robinson, the Surgeon General of the U.S. Navy, explained that preserving service members' and family members' psychological health is one of the greatest challenges faced today and that baseline resilience of soldiers is challenged by repeated deployments and long engagements. Robinson also explained that the decade of combat operations has led to an increase in the number of service members with TBIs.

A series of articles by Propublica has focused on the military's approach to treating soldiers who have experienced TBI and Post Traumatic Stress Disorder (PTSD). One article in the series follows five soldiers who were diagnosed with mild traumatic brain injury after an Iraqi rocket exploded near their trailer in 2009. A senior Army neuropsychologist, in Iraq to evaluate TBI assessment tools, persuaded the five men to enroll in his study, and they became the first documented cases of "pure blast" concussions- defined as mild traumatic brain injuries caused by the force of an explosion, instead of a secondary effect, such as slamming into a wall after an explosion.

An October 2011 report by the GAO to Congress analyzed DOD’s use of neurocognitive assessment tools to screen all service members after deployment for deficits or symptoms related to mild traumatic brain injury (mTBI). The GAO report explains DOD’s policies, the evidence DOD used to create its policies, as well as experts’ views on DOD’s policy. NextGov.com: "Battlefield brain-injury assessment tool has high failure rate"

U.S. Armed Services Committee "Military Health System Overview and Defense Health Program Cost Efficiencies" (Note: Discussion of ANAM begins at 99 minutes into hearing)

Propublica: "Aftershock: The Blast That Shook Psycho Platoon"


**Research Links PTSD with Dementia, Heart Disease**

Research conducted at the San Francisco Veterans Affairs Medical Center was presented in June 2011, at the fourth annual "Brain at War" conference. Researchers have found that combat veterans with post-traumatic stress disorder (PTSD) are twice as likely to have dementia and two to three times as likely to develop cardiac problems as compared to veterans without PTSD.

Researchers have found that combat veterans with post-traumatic stress disorder (PTSD) are twice as likely to have dementia and two to three times as likely to develop PTSD.

Dr. Michael Weiner, director of the Center for Imaging of Neurodegenerative Diseases at the Veterans Affairs Medical Center, explained that this could lead to a large increase in the number of veterans who develop Alzheimer's disease in the next 10 to 20 years. While there isn't a cure for Alzheimer's, researchers hope that by understanding how combat affects the brain, they can work towards improvements. For example, the hippocampus, devoted to short-term memory and learning new things, is significantly smaller in veterans with PTSD and researchers want to determine if this smaller section can grow as a result of therapy and treatment for stress.
A Veterans Administration Web Site features a searchable map of PTSD programs throughout the country, and the National Center for PTSD, administered by the VA, is working to advance the clinical care and social welfare for American's Veterans through research on PTSD. The Center also co-designed a downloadable phone app, "PTSD Coach" to connect veterans with information, resources, and tools to use to manage living with PTSD. San Francisco Chronicle: "Brains of vets with PTSD can change as they age"

VA PTSD Program Locator

National Center for PTSD

Veteran's Administration Program Gives Virginia Veterans a Consumer-Directed Budget
A Veteran-Directed home and community-based services (VD-HCBS) program in Virginia's Prince William County was profiled on InsideNova.com. The VA contracts with the Area Agency on Aging (AAA) to administer the VD-HCBS program and the veteran receives an assessment and care planning assistance from AAA staff and work with the staff member to select a mix of goods and services to meet their needs as well as their family caregiver(s). Through the program, veterans can hire their own caregivers, including family members. Veterans who want to participate in the program must first be referred to the AAA by the Veterans Administration Medical Center in Washington DC. The AAA director explains that this is one of two AAs in Virginia that offer VD-HCBS. InsideNova.com "0329 Program allows vets to direct own care"

RWJF Description of VA-HCBS Partnership Between VA and NRCPDSD

Research on Caregiving and Dementia

Caregivers and Relatives Perceive Care Differently
A study in the August 2011 issue of the Gerontologist interviewed 266 pairs of primary caregivers and their loved one with mild to moderate dementia. Each person was interviewed separately about five values: autonomy, burden, control, family, and safety. Adult children underestimated the importance of the five core values to their parents with dementia and that the discrepancies were associated primarily with the caregivers' beliefs about their loved one's involvement in decision making. The authors conclude that it is important for caregivers to gain a more accurate idea about their loved one's values and preferences in the earlier stages of dementia, since caregivers will become the surrogate decision makers as the disease progresses. PennState Release: "Caregivers and their relatives disagree about care given, received"

Gerontologist: "Understanding Discrepancy in Perceptions of Values: Individuals With Mild to Moderate Dementia and Their Family Caregivers" (abstract is free)

Stress level with MCI is Higher and Lasts Longer
A study in the July 2011 issue of The Journals of Gerontology of 30 spousal family caregivers for people with mild cognitive impairment (MCI) finds that the day-to-day challenges of caregiving can not only increase the levels of cortisol (stress-related hormone), but also leads to slower rates of decline of cortisol levels. The researchers called the 30 caregivers every day for a week to inquire about their days, interactions with their spouse and other family members, and about the loved one's behavior during the day. Saliva samples were also gathered on four of the days to measure cortisol levels. Dr. Tina Savla, the lead author, explains "Dealing with the day-to-day issues of living with a person with MCI can allow little time for recovery and may tax one's hypothalamic-pituitary-adrenal (HPA) system. The dysregulation in this system likely contributes to illnesses by further distressing the cardiovascular, metabolic, and immune functions." She adds that helping caregivers to learn effective stress management techniques early on may be especially helpful for caregiver's physical health and psychological well-being. The Journals of Gerontology, Series B: "Effects of Daily Stressors on the Psychological and Biological Well-being of Spouses of Persons With Mild Cognitive Impairment" (abstract is free)

EurekAlert: "Caregivers at risk for health problems"
FCA Fact Sheet: Mild Cognitive Impairment" (updated 2011)

Caregivers for Loved Ones with Alzheimer's Have Higher Health Costs
A report from the National Alliance for Caregiving analyzed data on 583 family caregivers taking part in the REACH 1 project who provided care in the home over an 18-month period. The average age of the caregivers was 61.7 years, 58% were white, 23% were African American, and 18% were Hispanic/Latino, 82.8% were female, and the average amount of care provided was 7.9 hours per day. The average duration was 4.3 years, while the average age of the care recipient was 78.7 years old. The authors use data from the Medical Expenditure Panel Survey (MEPS) to compare health care use and costs between caregivers with non-caregiver women.
Non-caregivers had 2.6 ER visits per 100 women (per month) as compared to 5.5 visits for caregivers, and doctor trips were also much higher at 95.5 per month (per 100 women) for caregivers as compared to 34.3 for non-caregivers. The authors calculate that the caregiving results in average health care costs of $4,766 more per month for caregivers.

**National Alliance for Caregiving: "CAREGIVING COSTS: Declining Health in the Alzheimer's Caregiver as Dementia Increases in the Care Recipient"

**Caregivers of Alzheimer's Patients**

A report by the National Alliance for Caregiving focuses on the positive and negative impacts of Alzheimer's disease on family caregivers. While past research has focused exclusively on the negative impacts of Alzheimer's on family caregivers, almost two-thirds of the 1,000 caregivers in this online survey report that caring for their loved ones gives them an opportunity to give back, while 46% of caregivers report feeling that they have a closer personal relationship with their care recipient. However, 61% of caregivers report feeling highly stressed, 40% report feelings of guilt for not doing more, and 39% report feeling angry at themselves for becoming frustrated with their loved one. Nine out of ten family caregivers report that their ability to recognize events and situations led them to suspect dementia or Alzheimer's disease, while only 31% report that a doctor's diagnosis contributed to their thought that Alzheimer's or dementia was present.

**National Alliance for Caregiving "What Made You Think Mom Had Alzheimer's?"

**Caregivers Adopt New Ways to Communicate When Loved Ones Have Dementia**

A survey by the National Family Caregivers Association finds that family caregivers biggest fear is a decline in their loved one's general health and physical decline, and their second biggest fear is Alzheimer’s taking away their loved one's ability to communicate. The online survey of 674 family caregivers for people with Alzheimer's found that caregivers adopted new ways to communicate (71%); and feel they have become better communicators (76%). Ninety-two percent of female caregivers said they rely on observing facial expressions to communicate, as compared to 82% for men. Other communication strategies include body language (79%) and using pictures/photos (66%). African-American (81%) and Hispanic (80%) caregivers were more likely to use alternative communication methods as compared to Caucasians (69%).

**National Family Caregivers Association: "New Survey Discusses Impact of Alzheimer's Disease on Family Caregivers"

**Adult Day Care Services Reduce Stress for Family Caregivers of Adults with Dementia**

A study in the June 2011 issue of *The Journals of Gerontology: Series B* provided 150 caregivers in New Jersey who care for people with dementia with 24-hour daily diaries and assessed their stress levels prior to their use of adult day care services. The care recipients attended the centers for an average of six hours a day for three days a week, with average activities including 30 minutes of physical activity, one-two hours of social activity, and one hour of activities focused on cognitive stimulation. At the beginning of the study, caregivers reported an average of two hours a day of behavior issues, but during the study, this number decreased significantly on days that the care receiver attended the adult day program. During the first month, behavior problems reduced to 75 minutes, and during the second month, 52 minutes. The authors note that this effect is driven in part because the person with dementia is at the day program (so the caregiver wouldn't experience the behavior problems), but also note that sleeping problems and behavior problems at home were reduced on days when the person attended the day care center. In contrast to past studies, their results indicate that the adult day care center didn't just "shift" stressors from one part of the day to another, but actually reduced stress and is an effective way to provide respite.

**Penn State Press Release: "Adult day care services provide much-needed break to family caregivers"

**The Journals of Gerontology: Series B Advance Access: "Effects of Adult Day Care on Daily Stress of Caregivers: A Within-Person Approach" (Abstract is free)

**Couples with Dementia and Decision Making**

A two-year research project is focused on decision-making for 21 couples in which one of the partners has dementia. The authors released some preliminary data about the study in September 2011 based on their interviews and home visits. They suggest that people with dementia want to continue making decisions when they're able to and recommend that professionals facilitate the involvement of people with dementia as much as possible. Decision-making patterns in the couples being studied are influenced by the couple's relationship prior to dementia, with the partner who always took the lead continuing to do so until they are unable. The spouses of people with dementia at times may take over decision-making, especially in cases of time sensitivity or if they believe they are lightening a burden on their spouse with dementia.

**ESRC: "Living with dementia and making decisions"**
Differences between Dementia Caregivers and Caregivers for Cognitive Impairment

A study in the March 2011 issue of the Journal of the American Geriatrics Society examines differences in caregivers for adults diagnosed with dementia and for caregivers of adults with cognitive impairments that are not dementia (CIND). Using data on 169 caregivers from the Aging, Demographics, and Memory Study (ADAMS), the authors find that dementia caregivers spend about nine hours a day caregiving, compared to four hours for CIND caregivers. Forty-four percent of dementia caregivers exhibited depressive symptoms as compared to 26.5% of CIND caregivers. Emotional strain experienced by CIND caregivers was driven by behavioral problems and difficulty with ADLs, while dementia caregiver emotional strain and depressive symptoms was driven by behavioral problems. The authors conclude: “The real caregiver burden of cognitive impairment in the U.S. population may therefore be greatly underestimated if people who have reached the diagnostic threshold for dementia are focused on exclusively.”

Journal of the American Geriatrics Society: Caring for Individuals with Dementia and Cognitive Impairment, Not Dementia: Findings from the Aging, Demographics, and Memory Study

Caregiver Attitudes towards Dementia Screening

A study in the Journal of American Geriatrics examines whether dementia caregivers have different attitudes about screening for dementia as compared to the general public. This topic is especially relevant given the recently updated guidelines for Alzheimer's disease that suggest looking at biomarkers of the disease in clinical trials. The New York Times explains that biomarkers are signs that a person may eventually develop the disease (blood pressure and cholesterol are biomarkers for heart disease), however, for Alzheimer's, more research is needed. For example, as high as one-third of people with amyloid plaque in their brains have not developed symptoms of Alzheimer's by the time they die.

The authors interview 81 participants with dementia caregiving experience and 125 participants without caregiving experience. Caregivers had lower acceptance of dementia screening (53.9% vs. 60.6% for non-caregivers) and also had a higher perceived suffering score (61.6% vs. 55.9%). However, there were not differences between caregivers and non-caregivers in perceived benefits of dementia screening, perceived stigma, or perceived negative effects on independence. Both groups reported that the top three barriers to screening are emotional suffering by the family (86% for caregivers; 75% non-caregivers); loss of driving privileges (75% for caregivers vs. 78% non-caregivers); and becoming depressed (64% caregivers vs. 43% non-caregivers).

Journal of American Geriatrics: "Caregiver and Noncaregiver Attitudes toward Dementia Screening" (abstract is free, subscription required for full article)

New York Times: Guidelines Allow Earlier Definition of Alzheimer's

The Importance of Getting a Diagnosis of Dementia

In Forbes Magazine, Carolyn Rosenblatt, an elder law attorney explains the importance of getting a diagnosis, which can help explain dementia-like behavior and ensure that medication interactions, infections, stroke, or even dehydration aren't to blame for memory or behavior problems. Using a friend's dad as an example, she provides four recommendations when a parent shows troubling behavior. They include getting a checkup from a reliable MD, preferably a neurologist who works with aging patients, locating and updating estate planning documents (while people are still competent to sign documents), planning ahead for possible care needs, and discussing the parent's situation with all of the family members during a family meeting.

Forbes: "The Danger Of Your Aging Parent Covering Up Dementia"

Doctors Should Give Financial Advice with Dementia Diagnosis

An article in the February 16, 2011 issue of the Journal of the American Medical Association suggest that doctors should play a larger role in giving families guidance on financial planning after delivering a diagnosis of dementia. The authors explain that currently doctors are unlikely to make suggestions, but given the rapid decline in a person’s ability to handle finances (when they are diagnosed with dementia), doctors should counsel families on financial planning, especially with the patient still has the capacity to make decisions.

Journal of the American Medical Association, Clinician’s Corner: “Finances in the Older Patient With Cognitive Impairment: ‘He Didn’t Want Me to Take Over’”

Practical Financial Advice for Family Caregivers

A New York Times article focused on probate, living trusts, and wills, and legal issues that family caregivers and their relatives should consider in long-term care and estate planning. Probate is the legal process used after a person dies to ensure that the will is legally valid and it creates a public record and people can opt to use a living trust to bypass the probate process. The authors explain that certain assets, including retirement assets, life insurance, and jointly titled bank accounts, brokerage account, and real estate will not go through probate, regardless of what a will or living trust instructs. The
authors also cite the example of a family caregiver who is listed jointly on a checking account in order to pay bills for a parent. If the parent dies, the money in the account automatically goes to the co-owner, and if a child attempted to share this money with her/her siblings, then it could be potentially be taxed as a gift. To avoid one child accidentally inheriting a checking account, a bank employee interviewed in the article suggests giving the family caregiver power of attorney instead. *New York Times: "Efforts to Avoid Probate Can Carry Their Own Risks"

**ER's Should Provide Better Care for Patients with Cognitive Issues**

A research review in the July 2011 issue of the *Journal of Advanced Nursing* examines the experience of older adults with cognitive impairments in visiting hospital emergency departments. The authors examine 15 studies published between 1994 and 2009 on patients from the US, Canada, Australia, Italy, New Zealand, and Israel, and find a lack of research on how these patients are assessed, treated, or supported during their visits. They find that delirium is the most common cognitive impairment, but is poorly recognized, difficult to identify, and often overlooked by physicians. They explain that there is debate about whether or not screening/detecting cognitive impairments should be done in ER's, who should do the assessments, and what provider obligations are after the assessment. They provide three recommendations, including improving the knowledge of healthcare professionals about cognitive impairment so that they can provide effective interventions, involving family caregivers to ensure that quality improvements are appropriate for the patient's needs, and they also suggest that a better screening tool, more appropriate for ER use, is needed.

*EurkAlert: "Emergency departments need to do more to support older adults with cognitive impairment"*

*Journal of Advanced Nursing: "Contextual factors influencing success or failure of emergency department interventions for cognitively impaired older people: a scoping and integrative review" (Abstract is free)*

*See Also:*

*Australia Institute of Health and Welfare: “Dementia among aged care residents: first information from the Aged Care Funding Instrument” (May 2011)*

*BMJ: “Efficacy of treating pain to reduce behavioural disturbances in residents of nursing homes with dementia: cluster randomised clinical trial” (July 2011)*

The fight against Alzheimer’s continues, and in 2011, it was spurred on by President Obama signing the National Alzheimer’s Project Act which will provide a roadmap forward in addressing how the U.S. responds to Alzheimer’s. Alzheimer’s was also focused on at the international level, both in terms of research for a cure, and in recognition of the impact the disease has on families around the world.

**New Guidelines will Allow Earlier Definition of Alzheimer’s**

In April 2011, new guidelines of the definition of Alzheimer’s disease were announced by the National Institute on Aging and the Alzheimer’s Association that will divide the disease into three stages. *The New York Times* noted that one of the most important aspects of the new guidelines includes adding biomarkers (such as abnormal levels of the proteins amyloid and tau) as indicators that somebody is likely to develop dementia eventually, though the guidelines are only recommended to be use in clinical trials.


*Alzheimer’s Association: "New Diagnostic Criteria and Guidelines for Alzheimer’s Disease"*

**132 Sessions Focused on National Alzheimer’s Plan**

The Alzheimer’s Association released a report focused on the results of 132 public listening sessions attended by 43,000 people across the U.S. to provide input on the National Alzheimer's Plan. In recognition of the political will necessary to achieve the goals, the report begins with a "thank you" to eight senators and representatives who helped introduce and pass the National Alzheimer's Project Act and a "thank you" for members of congress who attended listening sessions. The input from the listening sessions is grouped into ten issues, including insufficient research funding, poor dementia care, unprepared caregivers, and mounting costs.

*Alzheimer's Association: "Alzheimer's from the Frontlines: Challenges a National Alzheimer's Plan Must Address"*
Alzheimer's disease was Sixth Leading Causes of U.S. Deaths in 2007
The Center for Disease Control recently released data on the leading causes of American deaths, and Alzheimer's was ranked as the sixth leading cause of U.S. deaths in 2007. The data is divided by age, sex, and race, for example, Alzheimer's was the tenth ranked disease for males (accounting for 1.8% of deaths), but ranked fifth for females (accounting for 4.3% of deaths). National Vital Statistics Reports, Volume 58, Number 8 Deaths: Leading Causes for 2007

Every Sixty-Nine Seconds, Someone Develops Alzheimer's
According to a report by the Alzheimer’s Association, Alzheimer's is the sixth-leading cause of death in the U.S. and is the only disease in the top ten causes of death that cannot be prevented, cured, or even slowed. While death rates for most major diseases have declined from 2000 to 2008, deaths from Alzheimer's disease have risen 66 percent during the same time period. The impact on the estimated 15 million Alzheimer's and dementia caregivers is also large, with 60% reporting high levels of stress because of the prolonged duration of caregiving and 33% of caregivers reporting symptoms of depression. The financial impact is also large, with caregivers providing 17 billion hours of unpaid care (valued at $202 billion) and paying for $7.9 billion in additional health care costs. The report includes facts and figures for each individual state. Alzheimer's Association: 2011 Alzheimer Disease Facts and Figures USA Today: "Alzheimer's carries heavy toll on 15M unpaid caregivers"

Alzheimer's Report Shows Grim News for Boomers
According to a report, entitled "Generation Alzheimer's," ten million baby boomers will develop the disease during their aging process, and one in eight will die from it. The report predicts that the cost to the nation will be $20 trillion over the next 40 years, imposing a huge financial and emotional burden on American families. Beth Kallmyer, Senior Director of Constituent Relations for the Alzheimer's Association, said, "This long duration often places increasingly intensive care demands on the 11 million family members and friends who provide unpaid care, and it negatively affects their health, employment, income and financial security." Presently, every 70 seconds someone in America develops Alzheimer's and that number will increase by 2050 to every 33 seconds - without government intervention. Alzheimer's Association: "generation alzheimer's:

the defining disease of the baby boomers"

Medicare Expenditure for Patients with Advanced Dementia
A study published on the Archives of Internal Medicine website in January examined Medicare expenditures for 323 nursing home residents with advanced dementia. The authors find that the largest percent of Medicare expenditures were for hospitalizations (30.2%) and hospice (45.6%). For participants who passed away, mean Medicare expenditures increased by 65% in each of the last four quarters prior to death. The authors conclude that expenditures varied substantially and that strategies to promote high-quality palliative care may help shift spending away from aggressive treatments for patients at the end of life. Archives of Internal Medicine: "Medicare Expenditures among Nursing Home Residents with Advanced Dementia"

Research Links Depression and Belly Fat to Dementia
Two studies in the Journal of the American Geriatric Society focused on depression and belly fat and their relation to developing dementia. One study of 6,376 post-menopausal women aged 65 to 79 years old found that the 508 women who had significant depressive symptoms had about twice the risk for developing mild cognitive impairment and probable dementia as women who weren't depressed. In another study of 7,163 post-menopausal women aged 65 to 80, researchers found that excess weight on belly or hips is a risk factor for cognitive impairment and probable dementia in normal-weight women. Dr. Diana Kerwin, one of the authors of the study, explained that every one point increase in a woman's body mass index meant a decrease of one point in her cognitive test score. American Geriatric Society: "Older Women who are Depressed Have Twice the Risk for Developing Mild Cognitive Impairment and Dementia Later in Life" American Geriatric Society "Belly Fat“ Raises Cognitive Impairment and Dementia Risks for Older Women"

Mild Cognitive Impairment Research Update
The New York Times highlighted research on Mild Cognitive Impairment (MCI), a condition that is not as severe as Alzheimer's or other forms of dementia, though it may foretell these diseases. A study in the June issue of the New England Journal of Medicine by Dr. Ronald Petersen on MCI cited previous research that suggests between 10 and 20% of people older than 65 have mild cognitive impairment. Dr. Petersen explains two subtypes of the condition: amnestic and nonamnestic. Amnestic MCI is more common and is
associated with significant memory problems and forgetting important information and generally progresses to full-blown Alzheimer's. Nonamnestic MCI is associated with difficulty making decisions, finding the right words, visual-spatial tasks, and navigating. While the FDA has not approved any drugs to treat MCI, Dr. Petesen explains that Aricept and Namenda may be prescribed "off label." Family Caregiver Alliance recently updated its MCI Fact Sheet with information for family caregivers and their loved ones with tips about MCI, necessary transitions, and community resources. New York Times: "When Lapses Are Not Just Signs of Aging"

Minnesota: State Alzheimer's Plan Released
On January 13th, 2011, the Minnesota Alzheimer's Disease Working Group released a report entitled "Prepare MN for Alzheimer's 2020." The working group of 20 members was created as part of a state law that passed in May of 2009. The report includes 23 recommendations for the state legislature, state agencies, and the University of Minnesota. Proposals within the report include training and encouragement for doctors to detect Alzheimer's disease earlier, cognitive screening for all Minnesotans 65 and older in state-paid health programs, and a "dementia clearinghouse website." A number of states have also completed Alzheimer's state plans or are in the process of completing the plans. "Preparing Minnesota for Alzheimer's: The Budgetary, Social and Personal Impacts" Alzheimer's Association: "State Government Alzheimer's Disease Plans"

Utah: Alzheimer's Task Force Created
A bill (SB 48) was enacted in Utah in March 2011 that will create a task force to address Alzheimer's disease and other dementia in Utah. The task force will include 20 members, including somebody experiencing early-stages of dementia as well as a caregiver for a person with dementia. The task force is charged with assessing the current and future impact of Alzheimer's disease in Utah and developing recommendations for a November 2011 report. Utah joins 25 states that are currently developing Alzheimer's state plans, according to the Alzheimer's Association. The Salt Lake Tribune: "Alzheimer's task force created"
Utah State Legislature Website
Alzheimer's Association: State Legislation

Alzheimer's Association International Conference Highlights
A number of studies were presented at the conference this year, including a study from researchers at UCSF estimated that roughly half of the Alzheimer's cases in the U.S. could be attributable to behaviors or conditions that can be modified, including physical inactivity, smoking, depression, low education, hypertension, obesity, and diabetes. However, the authors caution that there isn't scientific proof that these risk factors cause Alzheimer's. Another study found that women in France, Germany, Spain, Poland, and the U.S. fear Alzheimer's disease more than any disease except cancer, possibly because they are also more likely to be caregivers for patients with Alzheimer's. The poll found that if roles were reversed, and the caregiver were to develop Alzheimer's, most felt that their spouses would care for them, however, men were more likely to indicate their wives would provide care while women were more likely to say they would rely on their children or paid caregivers. Women were also more likely to support government spending on research for a cure. Health Day "Women Bear Greatest Burden of Alzheimer's" New York Times "Grasping for Any Way to Prevent Alzheimer's" Alzheimer's Association Press Release: Research Advances from the Alzheimer's Association International Conference 2011

Lawmakers Urge UN to Include Alzheimer's disease in upcoming Health Conference
At a June 2011 hearing of the House Foreign Affairs Subcommittee on Africa, Global Health, and Human Rights, witnesses testified about the global impact of Alzheimer's disease. The disease currently affects 24-37 million people throughout the world, a number that could increase to 115 million by 2050. Representative Christopher Smith (R-NJ), the Chair of the subcommittee, agreed with advocates that Alzheimer's should be included at an upcoming United Nations summit in September on non-communicable diseases, and sent a letter along with Representative Edward Markey (D-MA), signed by 28 other lawmakers requesting that the UN add the disease to the conference agenda. Kaiser Foundation: "Experts Discuss Global Threat Of Alzheimer's Disease At House Subcommittee Hearing"

Canadian Program Recognizes Cultural Differences to Tailor Alzheimer's Care
A Canadian program serving the Onedia Nation of the Thames in Canada was profiled for its approach of tailoring Alzheimer's care. For example, the director of the program, Robin Shawanoo, explains that he conducts memory tests and ask participants to name the similarities between corn and squash, in contrast to colleagues in nearby London, Ontario, who ask participants about differences in a watch and a ruler. Dr. Kristen Jacklin is heading a research project into dementia in Aboriginal communities and explains that
Aboriginal communities have "a much more natural perception of the illness and one that is more accepting than mainstream society" and that First Nations communities view dementia as a natural, and often sacred, part of the aging process. In addition to incorporating Aboriginal symbols into dementia tests, Shawanoo also incorporates the culture into treatment and care by working with medicine people, using healing ceremonies and using sage. Shawanoo also suggests the importance of honoring the Aboriginal culture by recognizing not only the individual with Alzheimer's, but also their place within their family and community. *Edmonton Journal* "First Nation taking a cultural slant on treating dementia"

**Canada: Poll Finds Many Lacking in Knowledge of Alzheimer's**
A recent survey commissioned by the Alzheimer Society of 1,006 adults aged 45-65 found that many Canadians are lacking in their knowledge of dementia. Twenty-five percent of respondents could not name any of the symptoms of the degenerative brain illness, and only 50% identified memory loss as a key warning sign. While more than one-third of the respondents said they had been personally impacted by Alzheimer’s, their knowledge level was only slightly higher than those who had been unaffected by Alzheimer’s. *Globe and Mail:* "Canadians know way too little about dementia, survey finds"  
*Alzheimer Society:* "Alzheimer's disease...it's more than you think Canadian Society"

**Scotland: Funding to Improve Acute Hospital Care for Dementia Patients**
Scotland will receive a funding boost of £300,000 (approximately $483,339), to help fund improvement standards of acute hospital care for dementia patients. The Alzheimer's charity will use these funds to staff hospitals with specialist nurses. Alzheimer's Scotland had appealed to put a specialist nurse on every health board. Approximately 72,000 people in Scotland are estimated to have a diagnosis of dementia and that number is expected to double over the next 25 years. *BBC News:* "Alzheimer’s Scotland in £300,000 funding boost"

**United Kingdom: National Audit of Dementia Measures Hospital Care**
The Royal College of Psychiatrists was asked by the Healthcare Commission in 2006 to examine priority areas for improvement in services for people with dementia. As a result, a national, two-part audit of the care provided is being carried out, and the first report from this audit was released in December, 2011. *National Audit of Dementia*

**United Kingdom Survey: Hundreds Of Thousands Don't Receive Proper Care At Home**
The Alzheimer's Society recently released results of a survey of dementia patients receiving care at home. The report: "Support. Stay. Save. Care and Support of People with Dementia in their Own Homes," found 50% of people with dementia who live at home are without care or support services, and this substandard care will force 50,000 people into residential care homes or hospitals sooner than necessary. Carers reported in the survey that people living in their own homes with dementia were not being cared for, left bedridden, wearing unchanged incontinence pads and malnourished. Carers also said they themselves were put at risk of depression and stress because they were being left untrained to struggle on their own. Care staff responded positively to receiving specialized training and education to better provide for those suffering from the disease. *Alzheimer's Society:* "Insufficient care placing hundreds of thousands of people with dementia at risk"

**World Alzheimer's Report 2011**
Alzheimer's Disease International released its third annual report focused on Alzheimer's and the authors suggest that earlier diagnosis and intervention is preferred by people, may allow for more effective interventions, and may make better economic sense. The authors explain that most people receive a diagnosis later in the stages of the disease (if at all), creating a "treatment gap." Recommendations to address this gap include every country developing a national dementia strategy to promote early diagnosis and a continuum of care after diagnosis. In a review of economic analyses, the authors suggest that earlier diagnosis could create savings of up to $10,000 per patient in high-income countries. The authors also recommend all primary health care workers being trained in early detection of dementia, and where feasible, establishing specialist diagnostic centers for both diagnosis of Alzheimer's and formulation of care plans. *"World Alzheimer Report 2011: The benefits of early diagnosis and intervention"* (Executive Summary)

**The Economy and Family Caregivers**
The economic downturn not only impacted funding for programs supporting family caregivers, it also contributed to the overall financial challenges faced by family caregivers and their loved ones. In California, the Adult Day Health Care (ADHC) program, an optional Medi-Cal benefit, had allowed family caregivers to retain employment because they knew their loved ones were in a safe and supportive environment while they were at work. However, with the transition of this...
program to a smaller program that will serve fewer older, frail adults, more families will be forced to make difficult decisions about caregiving, employment, and institutional care.

In addition to reductions in programs that support caregivers, there have also been reductions to programs supporting care recipients. For example, the California Budget Project noted that state reductions to the Supplemental Security Income/State Supplementary Payment (SSI/SSP) program since 2008-09 are equivalent to a loss of roughly $3,600 for each of the 1.3 million Californians who rely on the modest cash benefit to meet basic living expenses.112

A report in the October 2011 issue of the *American Journal of Public Health* noted that more than 25% of people in mortgage default or foreclosure are 50 years old or older. Using data from the Health and Retirement Study, the authors found that of participants who were two or more months behind on their mortgage, 22% developed elevated depressive symptoms (compared to 3% for non-delinquent homeowners), 28% reported food insecurity (compared to 4%), and 32% reported not adhering to their medication due to costs (compared to 5%).113

The Greenlining Institute noted that many elders in California fall into the “eligibility gap” with incomes that are above the Federal Poverty Line, but below the Elder Index, which is an alternate measure of the cost of living for seniors that takes into account their higher medical costs. This “eligibility gap” means that seniors often don’t have enough money to cover their basic needs, yet are considered too “rich” to qualify for many public programs. Eliminating asset tests, or raising limits, would allow seniors to use safety net programs while retaining some savings.114

Sun Life Financial noted in its Unretirement Index that American’s confidence in retirement and government programs like Social Security and Medicare plunged from previous years. For example, only 23% of working Americans reported feeling confident that they would meet basic living expenses in retirement, a large reduction from the 42% in the previous year. Confidence in the future of Social Security was only 9%, also a large reduction from 22% in 2008, and confidence in Medicare benefits also sunk to 8% from 20% in 2008. In addition, 36% of Americans reported delaying routine or elective medical procedures in response to the economy, as compared to 20% in 2008. Forty-seven percent of boomers reported feeling “not at all confident” that would be able to take care of medical expenses in retirement.115

**Nine Million Americans Aged 50+ Face Risk of Hunger**

The AARP Foundation released a report that finds almost nine million Americans aged 50 and older face the risk of hunger- which represents a 79% increase from 2001. The risk of hunger for African Americans and Hispanics aged 50 and older is twice as high as for whites. People aged 50-59 who are at risk of hunger are 10% more likely to be disabled than people in the 40-49 age group or people age 60 or older. Adults aged 50-59 who are food-insecure are almost twice as likely to be diabetic, five times more likely to suffer from depression, and more than twice as likely to have at least one activity of daily living limitation (as compared to food-secure adults aged 50-59). *AARP Foundation: Food Insecurity Among Older Adults*

**Hearing on Older Americans Act and Senior Hunger**

A hearing in June 2011, focused on the Older Americans Act (OAA) and the role it plays in allowing seniors to age in place by connecting them with food and nutrition though programs including home delivered nutrition services, Congregate Nutrition Services, and Nutrition Services Incentive Program. Chairman Sanders (I-VT)

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released a report in conjunction with the hearing, and explained that he sees senior hunger as a financial and moral issue for the one million seniors who go hungry because they can't afford food. Senator Franken (D-MN) explained that drivers for programs like Meals on Wheels are often the only point of contact for people during the day, break isolation for the recipients, allow people to remain in their homes, and can be the first people to notice if/when seniors have emergencies. Assistant Secretary Greenlee explained that nutrition programs address not just the lack of financial ability to buy food, but also functional limitations for people who can't see, drive to a grocery store, or prepare their own meals. Greenlee also explained that every federal dollar is leveraged by three dollars at the state and local levels. Dr. Mary Jane Koren, a geriatrician, explained the importance of nutritious meals in preserving older adult's health, citing the examples of falls resulting in more injuries for adults who are not receiving sufficient nutrition. Assistant Secretary Greenlee explained that nutrition programs address not just the lack of financial ability to buy food, but also functional limitations for people who can't see, drive to a grocery store, or prepare their own meals. Greenlee also explained that every federal dollar is leveraged by three dollars at the state and local levels. Dr. Mary Jane Koren, a geriatrician, explained the importance of nutritious meals in preserving older adult's health, citing the examples of falls resulting in more injuries for adults who are not receiving sufficient nutrition. 

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**Rural Elders in California Face Higher Health Risks**

A report from the UCLA Center for Health Policy Research finds that the approximately 710,000 Californians aged 65 and older who live in rural areas face unique health challenges. Rural elders are more likely to be overweight or obese (61.3%) as compared to their urban (57.3%) or suburban (54%) counterparts. One in five rural elders do not engage in moderate or vigorous physical activity. In addition, one in five low-income older adults living in rural settings report that they cannot consistently afford enough food for the entire month, a rate that is about twice that of their counterparts in suburban areas. Rural adults also have higher rates of heart diseases and repeated falls. Policy recommendations, include senior walkability plans, using the internet for in-home monitoring, patient self-management, and online prescription ordering. They also suggest incentivizing primary care providers to work in rural areas, improving/expanding transportation services, and providing federal subsidies and loans for rural grocery stores and other food outlets.

**UCLA: "Out of reach? Rural elders have high rates of obesity, diabetes, heart disease"**

**Senior Poverty Increased from 2004 to 2008**

A July 2011 research policy brief from Demos and the Institute on Assets and Social Policy found that American seniors are facing increasing challenges making ends meet. Using the Senior Financial Stability Index, the authors find that economic insecurity among senior households increased from 27% in 2004 to 36% in 2008. Minority elders face the largest challenges: 52% of African-American and 56% of Latino senior households are economically insecure. Demos and IASP: “From Bad to Worse: Senior Economic Insecurity on the Rise”

**Census: 46.2 Million Americans in Poverty in 2010**

The U.S. Census Bureau released statistics on poverty, income, and health insurance coverage for 2010 in September, 2011. The real median household income dropped 2.3% from 2009 to $49,445, a level not seen since 1997. The nation's official poverty rate in 2010 (the poverty line was $22,314 for a family of four) rose to 15.1%, or 46.2 million Americans. An economist cited by the *New York Times* notes that this was the first time since the Great Depression that median household income, adjusted for inflation, has not risen over such a long time. In addition, 49.9 million Americans lacked health insurance coverage during 2009. Census Bureau: "Income, Poverty and Health Insurance Coverage in the United States: 2010" New York Times: "Soaring Poverty Casts Spotlight on 'Lost Decade'"

**Homeless Seniors Experience Higher Rates of Functional Decline, Falls, Frailty, Depression**

A study published online in the *Journal of Geriatric Internal Medicine* analyzed interview and physical examination data from 247 homeless adults aged 50 to 69 in the Boston area and compared the data to three large population-based study cohorts. Thirty percent of the homeless seniors reported difficulty with at least one ADL, more than half reported falling in the previous year, while almost 40% experienced major depression and 25% suffered from cognitive decline. The average age of the homeless in the U.S. is increasing, with almost one-third of homeless adults in the U.S. aged 50 or older, as compared to 11% in the 90s. The authors suggest that doctors should screen homeless adults for
age-related conditions earlier than adults who have not experienced homelessness.

**Families without Health Care Insurance Can’t Pay Their Hospital Bills**

A HHS report released in May 2011 found that uninsured families are mostly unable to pay for their hospital bills. This is driven in large part by the uninsured having no financial assets (the median asset level is $20 for all uninsured families). Fifty-eight percent of hospital stays result in bills of greater than $10,000. The authors note that hospitals will ask patients to pay their entire bills, but are often satisfied if they can collect even an amount equal to the cost of providing care (thus “breaking even”). On average, uninsured families are only able to pay the full bill for 12% of their hospitalizations they might experience, or, if only cost is considered, families can only pay 25% of the hospitalizations that they might experience.

HHS: "The Value of Health Insurance: Few of the Uninsured Have Adequate Resources to Pay Potential Hospital Bills"

**See Also:**

*Health Affairs*: “New 2011 Survey of Patients with Complex Care Needs in 11 Countries Finds That Care Is Often Poorly Coordinated” (November 2011)


**Brand Name Drug Prices Increase Dramatically in two Years Prior to Generic Competition**

A research brief from the AARP Public Policy Institute calls into question whether or not competition from generic drugs actually translates into lower prices for consumers. Using a "market basket" of 217 drugs that are widely used by Medicare Part D beneficiaries, the authors analyzed price increases for "brand name" drugs before and after the drugs went "off patent" and faced generic competition. While generic drug prices are on average 85% lower than the price of their brand name counterparts, drug manufacturers can delay their competitor's entry through "pay for delay" agreements with the first generic manufacturer who files for FDA approval, a trend that costs the American public $3.5 billion a year due to delays of price competition.

**AARP Public Policy Institute** "Retail Prices for Widely Used Brand Name Drugs Increase Considerably Prior to Generic Competition"
percent of participants had household income of less than $40,000 and 45% reported a significant or catastrophic financial burden due to out-of-pocket expenses. Out-of-pocket expenses totaled $1,266 a month and prescription medication represented the largest expense at $523 a month. In response, 47% of participants reported using all or part of their savings, 30% did not fill prescriptions, 20% took less medication than prescribed, and 40% borrowed money to pay for prescriptions. Patients experiencing greater financial burden also reported lower levels of satisfaction with their cancer care.

Kaiser Health News: "A Need For Health Care Reform: Cancer Care Costs And The Patient Perspective"

American Medical News: "Oncologists confront "financial toxicity" of cancer care"

ASCO 2011 Meeting Abstracts: "Impact of out-of-pocket expenses on cancer care"

Cancer Medications Come with Large Co-Payments
The Philadelphia Inquirer profiled a California woman who was shocked to find out that the monthly cost of her cancer drug was $2,400. A study cited in the May 2011 issue of the Journal of Oncology Practice found that almost 16% of Medicare beneficiaries with cancer did not fill their initial prescription to treat cancer, which is significantly higher than people with private insurance of 9%. In addition, 46% of Medicare beneficiaries faced co-payments of greater than $500, as compared to 11% of patients with private insurance.

Philadelphia Inquirer: “Seniors facing Medicare block on costly meds”

Legal and Financial Challenges in Battling Cancer
An article in the Chicago Tribune highlighted the financial and legal challenges that people with cancer (and their caregivers) often encounter. The article profiles the Cancer Legal Resource Center (CLRC), a joint initiative between the Disability Rights Legal Center and Loyola Law School Los Angeles. The program operates a national toll-free-assistance line (866-THE-CLRC) Chicago Tribune "Cancer patients get help through financial, health care mazes"

Increased Housing Costs Could Limit Ability to "Age at Home"
A September 2011 report from the AARP Public Policy Institute analyzes the impact of the mortgage meltdown on older Americans, and suggests that rising housing costs may challenge people's ability to remain in their homes. In addition, decreased property values may limit homeowner's ability to rely on a house as a financial cushion. The report analyzed homeowners with mortgages and without, as well as renters, and how "housing cost burdened" (defined as spending more than 30% of income on housing) the groups are. For homeowners aged 50+ with mortgages, 36% are now considered housing cost burdened, an increase from 29% in 2000. Fifteen percent of homeowners aged 50+ with mortgages are using at least 50% of their income for housing costs. For people aged 50 or older in the lowest income quartile (under $23,128), 78% of renters and 96% of homeowners with mortgages are housing cost burdened.

AARP PPI: "Housing for Older Adults: The Impact of the Recession"

One in Six Americans Live In Multigenerational Households
A December 2011, report from Generations United finds that an increased number of Americans are living in multigenerational households, due in part to the poor economy and also to an increasing number of elders living with family members who provide care. The authors explain that more than 51.4 million Americans of all ages live in a multigenerational household, a greater than 10% increase since the start of the recession in 2007. The reasons cited include the current economic climate (66%); job loss/change/underemployment (40%); health care costs (20%); and foreclosures or other housing loss (14%). Seventy-two percent of respondents agreed that this type of household arrangement improved the financial situation of at least one family member, while 82% agreed that the arrangement has enhanced bonds or relationships among family members. Seventy-eight percent report that the arrangement can be stressful at times, and 75% agree that it helps make it easier to provide for care needs of a family member (including child care, older adult care, or special medical care). Policy recommendations include changing housing systems to accommodate multigenerational families, increasing funding for the National Family Caregiver Support Program to $250 million, fully funding the Lifespan Respite Care Program, and enacting a federal caregiver tax credit.

Generations United: "Family Matters: Multigenerational Families in a Volatile Economy"

Practical Advice for “Doubled Up” Households
Michelle Singletary, a Washington Post columnist, addressed new Census numbers that 21.8 million Americans were "doubled up" for housing in 2011- a two million person increase from 2007, when only 19.7 million people were "doubled up." Her column provides some practical guidance for adult children living with their parents. Washington Post: "'Doubled-Up' households need clearly established roles"
AARP Sues HUD over Reverse Mortgage Policy

In March 2011, AARP sued the U.S. Department of Housing and Urban Development (HUD) over a policy that AARP says HUD changed in 2008. In 2008, HUD issued what it calls a "clarification" but AARP is calling a policy change. Under this new clarification/policy change, if one spouse took out a reverse mortgage and passed away and their surviving spouse is not on the reverse mortgage, then the surviving spouse must pay off the balance of the loan quickly if he or she wants to keep the home, otherwise the bank can foreclose.

Because of the housing meltdown, home values have fallen, and this could lead to a surviving spouse or heirs having to pay off a larger loan than the actual value of the house if they want to remain in the home. AARP sued on behalf of three surviving spouses who were facing foreclosure and argued that the 2008 change/clarification contradicts existing HUD rules as well as mortgage contracts and also suggested that the insurance required with reverse mortgages (HECM) exists so that a surviving spouse or heir would never have to pay more than the current value of the home.

According to the New York Times, HUD rescinded the 2008 order, however, AARP announced a new lawsuit against Wells Fargo and Fannie Mae in August 2011.

New York Times: "A Red Flag on Reverse Mortgages"

AARP: "HUD Targeted in Suit for Illegal Reverse Mortgage Foreclosure Actions"

New York Times: “AARP Files Another Reverse Mortgage Suit”


Median Income Declines with Age

A December 2011 report from AARP’s Public Policy Institute finds that median income declines steadily with age. In 2010, the median income for families where the head of household is 65-69 was $42,314, as compared to $21,305 for households headed by somebody aged 85 or older. Male-headed households had higher incomes than female-headed households, with a median income for widows that was only 75% of the median income for widowers.116

Unemployment Rates for Workers Aged 55 or Older Doubled Since 2007

An October 2011 report by the GAO found that unemployment rates for workers aged 55 or older doubled since 2007, and the percentage of older adults working part time who want to be working full time almost doubled. Approximately one-third of workers aged 65 and older are in low-wage jobs, defined as less than $10.20 per hour in 2007 or $11.00 per hour in 2010. For older workers who are laid off, they also have a harder time finding employment as compared to other age groups. The report authors also noted that older Americans may have less time for their retirements to recover from the downturn as compared to younger Americans, and that the low interest rates also mean less money for older adults who are more likely to rely on fixed income. Medical costs are higher for older adults, and when these are factored into poverty calculations, the poverty rates for older Americans increases from 9% to 17% in 2009. Poverty rates are higher for older women, Hispanics, and African Americans.

Income Security: Older Adults and the 2007-2009 Recession

Family Caregivers and Employment

There were some positive developments in support for employed caregivers in 2011, with successful paid sick day campaigns in several cities and the state of Connecticut.117 However, almost half of American workers lack paid sick days and the U.S. still lags behind the rest of the developed world in providing paid maternity leave. In Wisconsin, a bill was passed to nullify Milwaukee’s Paid Sick Days ordinance.118 Also, while the majority of employed family caregivers report that their employers knew about their caregiving situations, less than 25% of employees reported access to Employee Assistance Programs.119

Family Caregivers Forgo $303,880 in Lost Wages, Pension, and Social Security

The MetLife Mature Market Institute, the National Alliance for Caregiving, and the Center for Long Term


118 9 to 5 Milwaukee Website. Retrieved from http://www.9to5.org/local/milwaukee

Care Research and Policy released a report that details the financial impacts on caregivers who stop working. Using data on 1,112 people from the 2008 panel of the National Health and Retirement Study, the authors conclude that the total lost wages, pension and Social Security benefits for the 9.7 million adult children who are serving as caregivers in the U.S. equals almost $3 trillion. The authors explain that in a 1994 study, 3% of men and 9% of women reported providing care (defined as 100 hours or more of basic care in the past two years) and these figures more than tripled to 17% of men and 28% of women in 2008. Employees who are aged 50 are older are often in their prime earning years, and the authors suggest that people should consider not only the immediate impact of stopping work to be a caregiver, but also the longer term impacts of reduced retirement and social security benefits. The MetLife Study of Caregiving Costs to Working Caregivers

Wall Street Journal "Toll of Caring for Elderly Increases"

Caregiver Credits in France, Germany, Sweden Provide Lessons for US
A report by an analyst from the Social Security Administration examines caregiver credit components in retirement programs in three other countries. Caregiver credit programs are designed to support women who have a greater likelihood of leaving the workforce due to caregiving responsibilities (and therefore may receive less from government retirement programs like Social Security). In the United States, in 2008, 11.9% of women lived below the poverty line as compared to 6.7% for men, and rates are even higher for nonmarried (16.9%), widowed (15.4%), and divorced (19.5%) women. Based on his analysis, the author recommends four issues for consideration in designing caregiver credits, including the duration of years an individual will be eligible to receive credits; how credits will be calculated; who will be eligible (mother, father, or both); and whether a person has to leave the labor force completely to receive the credit. A blog posting by the author of the report, John Jankowski, was featured as part of FCA's 30 Days of Caregiving. Social Security Bulletin: Caregiver Credits in France, Germany, and Sweden: Lessons for the United States

Day 29: Protecting Caregivers through Social Security

Forty-Two Percent Lack Paid Sick Days
A fact sheet released in January, 2011, suggests that statistics on paid sick leave from the U.S. Bureau of Labor Statistics may provide an overly-rosy picture of access to paid sick leave in the U.S. The authors explain that while employees may be "eligible" for paid sick leave, many employees have not been at their jobs long enough to claim paid sick leave. On average, employees have to wait 78 business days (about 3 1/2 months) before they can access paid sick leave. Occupations like management have high rates of eligibility for paid sick leave and fewer low-tenure workers, leading to an 88% coverage rate for paid sick leave. However, employees in food preparation and serving related occupations have only a 23% coverage rate because fewer employers provide paid sick days in this industry and employee tenure is shorter. The implications of the research are important not only for flu and other outbreak prevention, but also for family caregivers who are also employed and may need sick days for themselves or relatives. 44 Million U.S. Workers Lacked Paid Sick Days in 2010: 77 Percent of Food Service Workers Lacked Access

U.S. Lags Behind 178 Other Developed Countries for Paid Maternity Leave for Mothers
A February 2011 report by Human Rights Watch found that the U.S. (other than New Jersey, California, and six cities) lags behind 178 other developed countries that have national laws guaranteeing paid maternity leave for mothers, while 50 countries also provide paid leave for new fathers. The U.S., Papua New Guinea, and Swaziland offer no legal guarantee of paid maternity leave, and only 11% of U.S. companies have opted to provide paid leave. While the FMLA does mandate the provision of unpaid, job-protected leave, it is only for eligible employees who have worked at least a year, have worked 1,250 hours, and who work for employers with 50 or more employees. Human Rights Watch: "Failing Its Families: Lack of Paid Leave and Work-Family Supports in the U.S."

California’s Paid Leave Programs and Policy Changes to Improve Access and Utilization
A guide from the Berkeley Center on Health, Economic & Family Security at the UC Berkeley School of Law and the Labor Project for Working Families provides an overview of California’s Paid Leave programs and limitations to the law that prevent more Californians from taking leave under the laws. According to the report, challenges to using the benefits under the program include strict eligibility rules, a lack of affordability, low public awareness, and limited enforcement/remedies of the laws. The authors suggest amending the rules for the CA Family Rights Act to broaden eligibility based on company size, annual hours worked, and job tenure. The authors also suggest broadening the definition of “family” in the CA Family Rights Act and the Paid Family Leave program and also increasing the amount and length of wage replacement. The authors also recommend protecting health insurance
coverage while women are on pregnancy leave, and this legislation was ultimately enacted. Finally, the authors suggest dedicating some resources to public awareness about the leave programs, and increasing enforcement of the laws. Reforming Family and Medical Leave Laws: Promoting Health and Economic Security for California’s Working Families

California’s Paid Family Leave Program
California was the first state in the nation to pass a comprehensive Paid Family Leave (PFL) program and a January 2011 report surveyed 500 employees and 253 employers to determine the law’s impact. The authors report: "Most employers report that PFL had either a "positive effect" or "no noticeable effect" on productivity (89 percent), profitability/performance (91 percent), turnover (96 percent), and employee morale (99 percent)." In terms of employees, the authors find that exempt employees (mainly managers and professionals) have more access than non-exempt employees to employer-provided benefits like paid sick leave, vacation, disability, and parental leave. From the sample of 500 survey respondents, the researchers also interviewed 50 employees who had experienced a "qualifying event" that should have been covered by the program, yet more than half of respondents didn’t know about the existence of the program and low-wage workers, immigrants, and Latinos were least likely to be aware of the program. Center for Economic and Policy Research: "Leaves That Pay: Employer and Worker Experiences With Paid Family Leave in California" Los Angeles Times: "California family leave program gets high marks in study"

Sacramento Bee Viewpoints: "Family leave program has proved its value, but it could do more"

California’s Experience Implementing Paid Leave
California started its Paid Family Leave Program in 2004, the first state in the nation to provide this type of leave for employees to provide care for a new child or to care for a seriously ill family member. More than one million Californians have used the program, and this guide provides an overview of how the program was implemented, along with suggestions for policymakers in states who may also be considering implementing paid leave. A Guide to Implementing Paid Family Leave: Lessons from California

CT: Paid Sick Days for Service Workers Approved
The Connecticut legislature voted in June, 2011, to approve a bill that would require companies with 50 or more employees to offer paid sick days. While the law covers the estimated 200,000 to 400,000 service workers who receive an hourly wage, it exempts manufacturing companies, nationally chartered nonprofit organization, day laborers, independent contractors and temporary workers. An employee will be able to earn one hour of paid sick time for every 40 hours worked, however, it is capped at five days a year. New York Times: "In Connecticut, Paid Sick Leave for Service Workers Is Approved"

Massachusetts: Husband Fired for Asking to Schedule Work around Wife’s Cancer Appts.
ABC News focused on a man who is a caregiver for his wife with lung cancer and who was allegedly fired for requesting a more flexible work schedule to enable him to provide care to his wife. Carl Sorabella, an accountant for a real estate company in Massachusetts, had worked for the company for 14 years. According to Sorabella, he requested a flexible schedule so that he could accompany his wife to medical appointments, and the following week he received notice that he was fired. David Frank, a legal analyst with Lawyers Weekly, was interviewed for the story and explained “This is not an unprecedented situation,” and cited the fact that the Family Medicaid Leave Act (FMLA) only covers employers with 50 or more employees. Sorabella estimated that his company employs 20 people. ABC News: "Man Says He Was Fired After Telling Employer His Wife Has Cancer"

North Carolina: Better Employment Supports for Family Caregivers in North Carolina
A report from the North Carolina Justice Center provides policy recommendations for state leaders to better support family caregivers who are providing child care and elder care. Recommendations include paid sick leave, family leave insurance (currently offered in NJ and CA), broadening the definition of family beyond the Family Medical Leave Act, and more flexibility in the workplace. The authors also suggest that Family Responsibility Discrimination is a growing issue in North Carolina and nationally. Two laws that have been introduced in North Carolina are cited in the report, including a paid sick days bill and a bill that would broaden the FMLA’s definition of family. NC Justice Center: "Time to Care: How North Carolina Can Promote Health, Support Workers, and Strengthen Families"

Philadelphia: Paid Sick Days Enacted
The Philadelphia City Council enacted Paid Sick Days in the fall of 2011. Mayo Michael Nutter had vetoed a more expansive paid sick days bill earlier in the year, but neither vetoed nor signed a more limited Paid Leave bill, thus it became law. Paid Sick Leave Mandated for Many Employers in Philadelphia
Seattle: Paid Sick Days Enacted
The Seattle City Council approved legislation in September, 2011, to mandate paid sick days for all businesses with at least five full-time employees starting in September 2012. Employees can use the sick days to care for themselves or an ill family member. The sick days will accumulate at one hour for every 40 hours worked at smaller (5-49 employees) and mid-size (50 to 249) companies, and will accumulate at one hour for every 30 hours worked at large (250+) companies. Smaller employers (5 to 49) will have to provide at least five days of paid sick leave annually, while employers with 50 to 239 employees will have to provide at least seven paid sick days, and larger companies (250+) will have to provide at least nine sick days annually. New companies that are less than two years old will be exempt. Seattle joins San Francisco, Washington DC, and the state of Connecticut in mandating paid sick days. The council president, Richard Conlin, was the only person who voted against the leave, citing the fact that 39,000 "very small" companies will be exempt, and that the sick-leave requirement can be waived as part of collective bargaining. Seattle Times: "Seattle approves paid sick-leave requirement"

Canada: Caregiving Leave Legislation Introduced
The Canadian Press reports that legislation expanding a caregiver leave program was introduced in December, 2011. The legislation would extend an existing program that provides up to 8 weeks of unpaid leave for people caring for a loved one who is dying to also include caring for a family member with a serious injury or illness. The bill would also make the caregiver leave time eligible for employment insurance benefits, a provision currently in place for the family medical leave plan. The political outlook for the bill remains uncertain because the Liberal party would need the support of at least one of the opposition parties in order to get the bill passed. The Canadian Press: "Liberals introduce caregivers bill"

United Kingdom: Caregiver Widower Sues Because Widowers Receive Less Pension than Widows
A widower in the United Kingdom, Ian Cockbrun, is suing the Department of Health because he receives £3,200 less ($5,200) annually in pension than a widow would in the same situation. His wife passed away in 2007, and Mr. Cockburn argues that his wife's contributions to the pension system should be treated in the same manner as a man's contributions. When the Department of Health calculates pensions, it discounts contributions made by deceased wives before April 6, 1988, whereas widows' pensions are based on the full contributions by their husbands. This provision is in place because of women's lower earning potential and child-care responsibilities placing them at an economic disadvantage. A number of studies have also found that caregivers are more likely to be women. However, in Mr. Cockburn's case, he had stopped working to serve as his wife's full-time caregiver while she battled cancer. If he is successful, the result could be the Department of Health paying an extra £1billion a year to widowers. Telegraph: "Bereaved husband claims sex discrimination over NHS pension"

Pay for Long-Term Care
Research on the financial toll of caregiving continues to suggest that the system of long-term care in the United States is heavily reliant on an uncompensated workforce of family caregivers who often sacrifice their own financial security to care for a loved one. Families continue to face sticker shock when faced with the cost of long-term care, with the national average cost of nursing home care at 241% of the average annual household income of older adults.120 While some suggest long-term care insurance is a possible strategy to mitigate costs, thus far it has had little uptake by consumers, with HHS noting in its report on CLASS that less than 3% of Americans have purchased such insurance.121 While there was a slight increase in consumer knowledge about the differences between what Medicaid and Medicare will pay for, most Americans do not know the difference until they are confronted with understanding it as part of their care for a loved one.

Differences in Opinion for Retirees and Pre-Retirees on Importance of Medicare/Medicaid
A study conducted by National Public Radio, the Robert Wood Johnson Foundation and the Harvard School of Public Health examined retiree and pre-retiree attitudes about retirement, health, finances, and other issues. Despite the fact that Medicaid pays for the majority of long-term care, only 38% of pre-retirees and retirees "expect that Medicaid will be very important for them personally during their retirement," while the numbers jump to 65% (pre-retirees) and 74% when speaking about Medicare. Another question asked "If you (or your

spouse/partner) were to need care in a nursing home for three months (100 days) or more, how would the majority of costs be paid?“ Thirty-two percent of pre-retirees answered Medicare and 43% of retirees answered Medicare, while 10% of pre-retirees answered Medicaid and 7% of retirees answered Medicaid.

Retirement and Health Poll

2011 Survey of Long-Term Care Costs
Genworth Financial released its annual survey of the costs of long-term care in May, 2011. According to the survey, the median annual cost of a room in an assisted living facility was $39,135 in 2010, while a private nursing room home was $77,745. The median hourly cost for home health aide services was $19 per hour, while homemaker services were $18 an hour. The report website includes an interactive state map that displays costs in each state. Genworth Financial 2011 Cost of Care Survey
See also: Market Survey of Long-Term Care Costs The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs (October 2011)

Women are also more likely to need long-term care, with an average bill of $124,000 vs. $44,000 for men.

Income (from all sources) during retirement for men aged 65 and older is $37,509, while women's income is only 57% of that amount: $21,509.

Bargaining On Long-Term Care
The Wall Street Journal featured advice on how to bargain when shopping for long-term care. The author suggests using resources like a map prepared by Genworth Financial to comparison shop on local costs of long-term care. According to Genworth's annual survey of long-term care costs, the cost of in-home care stayed about the same from 2010, but assisted living increased 2.4% to an average of $3,261 per month (for a one-bedroom) and the cost of a shared nursing home room increased 5.7% to $193 per day. Financial advisors interviewed in the story suggested negotiating prices using several strategies, including getting quotes from several organizations and checking to see if there are waiting lists- if they don't have a waiting list, they may be willing to negotiate because they want business. For consumers who are paying out-of-pocket, it may be possible to negotiate for extra amenities like a private room. For home-care services, advisors suggest asking for a discount if competitors offer lower rates and asking for a discount for weekend services if a consumer is already contracting for a high number of hours.

WSJ: "Driving a Bargain For Long-Term Care"

Two-thirds of Americans Believe in Planning for LTC, but less than Half Make Plans
A survey released by Lincoln Financial Group in January, 2011 examined attitudes of Americans towards planning for the financing of long-term care. For survey participants who had overseen the long-term care of a loved one, 83% said their loved one’s lifestyle changed significantly to pay for their care, with more than one-fifth of respondents reporting that they had personally helped pay for the costs of care. Of participants who were caregivers, 93% reported using their own income to help pay for care, 72% personally provided care in a loved one’s home, 53% brought their loved one into their home, and 48% used their own savings to help pay for care.

Lincoln Financial Life Stages Survey: Long-term care
Time Magazine: “Preparing for Long-Term Care: Any Good Options?”

Report on Lack of Long-Term Care Planning
Volunteers of America released a report in April 2011 that brings together data on the current cost of long-term care and American's plans (or lack thereof) for financing their own long-term care. The report incorporates data from an earlier survey of caregivers, for example, 40% of caregiver respondents aged 45-65 were "extremely or very worried" about saving enough for a financially secure retirement, as compared to 34% of the general population. In addition, 46% of caregivers were "extremely or very worried" about having secure health insurance for your family, even with a job loss, whereas only 37% of the general population was "extremely or very worried."

Volunteers of America: "Boomer Bust 2011: Still Unprepared and Unaware"

Women Know They Face Longer Retirements and Higher LTC Costs
A September 2011 report from the MetLife Mature Market Institute and Scripps Gerontology Center addresses differences in retirement planning for women based on their longer lifespans, higher likelihood of being a caregiver, and increased chances of utilizing long-term care. The report is based on a national survey of 1,007 retired and employed men and women aged 50
to 70. Women are more likely than men to be widowed, divorced, or otherwise live alone. Women (71%) are more likely than men (63%) to report being either very or somewhat concerned about providing for their own or their spouse's long-term care needs. Women are also more likely to need long-term care, with an average bill of $124,000 vs. $44,000 for men. Income (from all sources) during retirement for men aged 65 and older is $37,509, while women's income is only 57% of that amount: $21,509. The authors provide case studies as well as a section on "Implications for Women (and a few notes for men)" that provides practical advice on financial planning that accounts for women's longer lifespans and higher likelihood of providing and needing LTC. The MetLife Study of Women, Retirement, and the Extra-Long Life"

Survey Finds Two-Thirds of Californians Worry about Cost of Long-Term Care
A survey released in August, 2011 by the Scan Foundation and the UCLA Center for Health Policy Research of 1,490 Californian voters aged 40 and older found that 2/3 of respondents worry about the cost of long-term care and 2/3 could not afford more than three months of nursing home care if they were paying for it themselves. Thirty-eight percent of survey respondents reported having been a caregiver in the past 12 months, with 63% reporting that it is emotionally stressful, and 29% reporting financial hardships due to caregiving. Ninety percent of respondents had not heard of the CLASS program, though after hearing a description of it, 88% of respondents said they strongly or somewhat favor the program.

Scan Foundation/UCLA Center for Health Policy Research: "Poll Finds California Voters 40 and Older Are Struggling to Make Ends Meet and Financially Unprepared for Growing Older"

Californians Are More Knowledgeable about LTC Costs, but Doesn’t Translate to Action
A survey released in September 2011 by the California Partnership for Long-Term Care finds that while consumers are more knowledgeable about long-term care costs, this hasn't translated to Californians purchasing long-term care insurance policies. The reason most cited by survey respondents for not buying long-term care insurance was that it would cost too much (59.2%), followed by 54.7% of respondents who said "my family and I haven't really given much thought to purchasing insurance to pay for long-term care expenses." The survey did not ask about LTC insurance premium increases, though 28.8% of respondents agreed with the statement that "long-term care insurance companies cannot be trusted to pay for the benefits they promise to provide" as a reason they had not purchased long-term care insurance.

CA Partnership for Long-Term Care Survey Results

LTC Insurance Consumption is Low, Partly Because of Medicaid
A National Bureau of Economic Research working paper addresses long-term care as one of the largest "uninsured financial risks facing the elderly in the United States." The authors use a typical LTC insurance policy (with a 60-day deductible, 4 year benefit period, $150 max. daily benefit) to calculate the "load" on the policy- in other words, how much a person pays in premiums relative to how much they can expect to receive in benefits. For this typical policy, purchased at age 65, if the policyholder paid the premiums until they died, the load is 32 cents on the dollar. For every dollar paid by the person, they can expect to receive back 68 cents in benefits, which the authors suggest is fairly high compared to annuities (with "loads" of 15 to 25 cents) or group health insurance (6 to 10 cents). The authors suggest that Medicaid is a "highly imperfect form of insurance as it essentially comes with a deductible of nearly all of your income and assets." Medicaid is included as another reason for low LTC insurance consumption. The authors suggest that for a 65 year old male at the median of the wealth distribution who has a LTC insurance policy, 60% of the expected value of benefits are redundant of benefits that would have been paid by Medicaid absent a LTC insurance policy. They suggest that if all states moved to the most stringent asset tests possible (under federal law), then the average amount of household assets protected from Medicaid would decrease by about $25,000, and LTC insurance uptake would increase by 2.7%. NBER: "Insuring Long Term Care in the US"

RWJF: Partnership for Long-Term Care Program Results Report

Issues in Planning an Inheritance for Disabled Heirs
The Wall Street Journal addressed estate planning for parents whose children have a chronic disability. Supportive programs like Medicaid often include asset and income tests that parents need to consider to avoid accidentally disqualifying their adult children through an inheritance. The supply of housing...
for adults with disabilities has not kept up with demand, and according to an ARC report, 2/3 of parents/caregivers don't have a plan for where the person they support will live when they are older. The article suggests one possibility to address housing for a disabled adult is to use a trust to pay the mortgage and property taxes. Special needs trusts are another strategy for parents to "spend down" to a level where they (the parents) will qualify for long-term care services without being penalized by Medicaid "look back" provisions. Another possibility is leaving an inheritance to a sibling who can serve as the caregiver, though if the sibling divorces, that money could ultimately go to an ex-spouse instead of the adult disabled child.

Wall Street Journal: "Taking Care of Disabled Heirs"

Healthcare and Family Caregivers

Research in 2011 focused on a variety of healthcare issues faced by family caregivers and their loved ones, including prescription drugs, the limited supply of geriatricians, improving communication between doctors and patients, and the amount of time doctors in the U.S. spend submitting paperwork to multiple insurance companies.122

Research also addressed the role of medications in treating patients in nursing homes with dementia, and the New York Times profiled a nursing home in Minnesota that had successfully piloted an alternative approach to antipsychotic medication that is now being implemented in 15 other nursing homes administered by the same non-profit.123

Canada: Twenty-Three Percent of Seniors Take Ten or More Medications Every Day
The Toronto Star highlighted a report that focuses on elder Canadians and their health care. The report, Health Care in Canada, 2011: A Focus on Seniors and Aging, addresses current issues challenging the provision of

care. While seniors represent 14% of the population, they use 40% of hospital services and account for 45% of all provincial and territorial government health spending. The authors also note that seniors account for 85% of patients who are considered "alternate level of care stays" - meaning they have completed their acute care phase of their treatment, but remain in an acute care bed, with 47% of seniors waiting to be moved to a long-term care facility. Sixty-three percent of senior Canadians took five or more prescription drugs in 2009, with 23% taking ten or more medications. In addition, one out of ten seniors are taking medications from the Beers list, which is an internationally recognized list of drugs that should only be taken by seniors if there are no alternatives. Toronto Star: "One quarter of seniors taking 10 or more medications"

CIHI Report: "Health Care in Canada, 2011: A Focus on Seniors and Aging"

United Kingdom Study: Drug Combinations Can Increase Risk of Dying
A study by British scientists and featured in the Journal of the American Geriatrics Society examined 20 years worth of data on more than 13,000 people aged 65 or older and their experience with 80 common medications that can cause serious health problems when they are used together. The drugs were assigned grades based on how effectively they block a chemical in the nervous system called acetylcholine, and the more effective a drug is at blocking this chemical, the more dangerous it is in high doses. High risk drugs were assigned three points, and low-risk drugs were assigned one point, and for patients who took a combination of drugs that totaled four points or greater, there was a 20% chance of dying within two years as compared to 7% for people over the age of 65 who were not taking drugs. The authors suggest that the risk of dying increased 25% for each additional point accumulated.

The Telegraph: “Fatal cocktail of common drugs putting elderly at risk”


Efforts to Increase Medication Adherence
The Wall Street Journal examined efforts to increase medication adherence. Citing a medication adherence failure rate of nearly 50% for Americans, with 20-30% not filling medications, the Journal highlighted efforts to use case managers, phone calls, reminders, and counseling to ensure that patients take their medications.

Kaiser Permanente Colorado uses electronic health records linked to its pharmacies, and found that this
linkage meant that only 7% of patients (for hypertension, diabetes, and high cholesterol) didn’t fill their prescriptions as compared to 22% in non-linked systems. \textit{Wall Street Journal}: “Many Pills, Many Not Taken”

**Rehospitalizations Reduced with Intervention**

The June issue of the \textit{Journal of the American Geriatrics Society} featured a study which used a three-pronged intervention approach to reduce avoidable rehospitalizations for patients being discharged from a skilled nursing facility (SNF). The intervention includes a standardized template for physician admissions procedures, palliative care consultations for patients with three or more hospital admissions in the past 6 months, and root-cause analysis conferences for patients transferred back to the hospital that are conducted on a bi-monthly basis. The intervention took place at a SNF with 50 beds, and included 862 patients (baseline) and 863 patients (who received the intervention) who were admitted to the SNF from acute care hospitals between June 2008 and May 2010. For patients who received the intervention, readmissions to acute care declined (from 16.5% to 13.3%), and patients were more likely to die at the SNF in accordance with their wishes than to be transferred out to a hospital. Discharges to homes also increased from 68.5% to 73%, and discharges to long-term care dropped to 11.5% from 13.8%. “The change in discharge disposition observed between the two periods, we believe, reflects an improvement in patient outcomes,” says lead author Randi E. Berkowitz, M.D. \textit{Journal of the American Geriatrics Society}: “Improving Disposition Outcomes for Patients in a Geriatric Skilled Nursing Facility” (abstract free, subscription required for article) EurekAlert: “Reducing avoidable rehospitalizations among seniors” \textit{USA Today}: “Better-informed patients can help cut costs, study shows”

**Eighty-Three Percent of Antipsychotic Prescriptions for Residents for "Off-Label" Use**

An audit by the inspector general of the Department of Health and Human Services found that antipsychotic prescriptions were given to elderly nursing home residents, especially those with dementia, even though the drugs increase the risks of death and are not approved to be used in this manner. According to a medical record review, from January 1 to June 30, 2007, fifty-one percent of Medicare claims for antipsychotic drugs were erroneous, totaling $116 million. The investigation also found that 88% of the Medicare claims for antipsychotic medications for elderly nursing home residents were associated with the condition specified in the FDA boxed warning (i.e. dementia). According to the report, 14% of the 2.1 million elderly nursing home residents had at least one claim for these types of drugs. The report suggests that CMS collect information on the diagnoses given to Medicare patients in order to analyze whether the drug prescriptions are appropriate. \textit{HHS}: "Medicare Atypical Antipsychotic Drug Claims for Elderly Nursing Home Residents" \textit{NYT}: "Antipsychotic Drugs Called Hazardous for the Elderly"

**Geriatricians Limited, Especially in Rural Areas**

A study in the \textit{Journal of the American Geriatrics Society} uses county-level data on the number of geriatricians, family physicians, and general internists and compares this with U.S. Census data on the number of adults 65 years or older. The authors report that in 2008 there were an average of 1.07 geriatricians per 10,000 elderly residents, 22.17 family physicians and 13.94 general internists per 10,000 older adults. The authors suggest that non-geriatrician doctors, as well as nurse practitioners and physicians assistants will provide the bulk of the care. They also suggest that Medicare could help with creating new models by providing incentives for geriatrician training, compensating doctors for the complex care necessary for very frail older adults, increasing geriatric education for all residencies, and providing higher payments to medical homes to deliver and integrate complex care for elderly Americans. \textit{USA Today}: "Elderly Face Lack of Geriatric Specialists, New Report Warns" \textit{Journal of the American Geriatrics Society}: "Rural-Urban Distribution of the U.S. Geriatrics Physician Workforce"

**Med Schools Consider Communication Skills**

The \textit{New York Times} focused on eight medical schools in the U.S. that have begun requiring communications skills tests from potential applicants. Virginia Tech Carilion, the newest medical school in the country, is profiled for its process of nine brief interviews that require applicants to demonstrate they have social and communication skills to navigate a medical field that is shifting to a team approach. Candidates come to the school on a Saturday in March and are lined up with their backs to the doors of 26 interview rooms. They are given two minutes to read a summary of an ethical challenge, and are then asked to discuss the challenge for eight minutes with an interviewer and to repeat this process eight more times. Sample questions include whether giving patients unproven alternative remedies is ethical, and whether insurance co-pays for medical visits are appropriate. During the interview, graders are attempting to analyze the applicant's ability to listen, communicate, and work on a team where people may disagree. The \textit{New York Times} suggests that schools are
prioritizing good communication because of research that finds poor communication among doctors, patients, and nurses is to blame for a large number of preventable deaths.

New York Times: "New for Aspiring Doctors, the People Skills Test"

UK Royal College of Nursing Suggests Extending Hospital Hours So Caregivers Can Help
A proposal by the Royal College of Nursing (RCN) to extend hospital visiting hours to enable caregivers to become more involved in a patient's care created controversy over the roles of family caregivers and hospital staff. While the head of the RCN said he didn't want caregivers doing nurses' tasks, he did think that caregivers could assist with things like making mealtimes less stressful for patients. The chief executive of the Patients Association suggested that "It is just the tip of the iceberg," and said patient care, including feeding and toileting should be carried out by nurses. A critique of the proposal by a journalist suggested that visitors can be disturbing for other patients on the ward and that lengthening visiting hours would exacerbate the problem. She also suggests that a stronger focus on providing care for people without acute medical problems outside of the hospital would do more to address the current burden on nursing staff for older people who shouldn't be in acute care hospital beds.

The Guardian: "Don't ask relatives to fill the elderly care gap"

BBC: "RCN wants longer hospital visiting hours"

Guardianship Needs Improvement
A GAO report examines guardians who are appointed by the Social Security Administration, Veterans Affairs, and state courts and compared the screening procedures, laws, and information sharing between these three programs. The GAO suggests that there is room for improvement in guardianship monitoring by state courts and information sharing between the three entities.

GAO: "Incapacitated Adults: Oversight of Federal Fiduciaries and Court-Appointed Guardians Needs Improvement"

Canada: More Elderly Placed Under Care of Public Advocate Because Of Family Disputes
The Victorian Public Advocate program has seen a 10% increase in the number of elderly Victorians placed under its care in the past financial year, partly due to families who are taking disputes to the program. Guardianship through the program was introduced in 1986 with the goal of protecting people with intellectual disabilities without families to care for them. A Public Advocate explains that there are currently 50 people on the waiting list for a guardian and that 35% of the current 1,574 guardianship cases are due to dementia. She suggests that family members are often in conflict over money, where care should be provided, and medical decisions.

The Age.Com AU: "Guardians for old in big demand"

FCA Fact Sheet: "Caregiving with your siblings"

CO: One of Four States without Mandatory Reporting of Suspected Elder Abuse

The Denver Post profiled the efforts of an 82-year old advocate who is lobbying for Colorado to adopt mandatory reporting requirements for social workers and physicians who suspect elder abuse. Legislation mandating the reporting has been introduced on multiple occasions during the past 13 years but has not been enacted, including a 2005 veto by then Governor Bill Owens. A district attorney profiled in the story supports the law, and since opening an office in February 2010, has prosecuted 35 cases of elder abuse. Colorado's Adult Protective Services received 10,846 reports in FY 2010-11 and opened 4,481 cases. Caseworkers had an average caseload of 31 per worker, though the national recommended standard is 25. For more information, visit:

Denver Post: "Colorado advocates push mandatory reporting law for elder abuse"

See Also:

World Health Organizations: “European report on preventing elder maltreatment” (2011)"

“A Total Indifference to our Dignity” Older People’s Understandings of Elder Abuse (May 2011)
Family Consultants . . . began using iPads in 2011 in meetings with family caregivers. [They] can watch videos of practical skills . . . see examples of assistive devices, learn communication skills for loved ones with dementia, and see a video of a typical day at an adult day center.

Technology and Caregiving

Technology’s potential impact on caregiving continues to move forward. Several cities and nursing homes began using GPS devices to locate people if they wander as a result of Alzheimer’s. Beyond GPS devices, new possibilities also opened up, including doctors allowing their patients to see their medical notes, telehealth technologies, iPads being used at nursing homes to engage residents, applications for smart phones to track health, and technology that can allow seniors to age in place while their health is remotely monitored by family members or healthcare professionals.

Family Consultants in Family Caregiver Alliance’s local program, the Bay Area Caregiver Resource Center, began using iPads in 2011 in meetings with family caregivers. At the consultations, caregivers can watch videos of practical skills like transferring; see examples of assistive devices; learn communication skills for loved ones with dementia; and see a video of a typical day at an adult day center.

Social media, especially Facebook, is also viewed as a tool for caregivers who can use it to seek advice, provide updates to family and friends on a loved one’s condition, or to seek support.124 Oklahoma’s first-in-the-nation launch of fully automating their Medicaid process to allow people to apply online for Medicaid, or Minnesota’s new “instant messaging” capabilities in its state information and referral line suggests that when sufficient resources are available, government should use technology as a tool to make life easier.125 However, Colorado and Indiana’s experiences with changing their benefit application systems highlight the very real, human, consequences when programs are not implemented correctly or safeguards are not included during transitions to new programs.

Caregivers: What Technology is Useful to You?
The National Alliance for Caregiving and UnitedHealthcare released the results of a survey of caregivers about their interest in using technology to support their caregiving roles. The survey included 1,000 participants who provided at least five hours of care a week and already use technology. The three most popular technologies among survey respondents included: (1) Personal health record tracking system for tracking medications or testing; (2) Caregiving coordination system to log a care recipient’s medical appointments or for scheduling family members or volunteer's time; and (3) Medication support system, a device to remind patients to take medications and provide helpful information about possible side effects. UnitedHealthcare and NAC: "The e-Connected Family Caregiver: Bringing Caregiving into the 21st Century"

Grants to Implement Mobile Health Technologies

The Center for Technology and Aging awarded grants to five organizations who will use the funding to explore the best ways to implement mobile health technologies for older adults with chronic health conditions. The center released a paper earlier this year that examines how cell/smart phones, laptops/tablet computers, and other mobile-enabled devices can be used by older Americans, their caregivers, and their doctors to better manage chronic diseases, use medications properly, and avoid safety risks like falls. The authors suggest that technology could also result in better healthcare quality, lower costs, and less burdens on family and professional caregivers. The grants include a project to prevent/delay transitions of Medicare members with heart disease to higher levels of care settings; a tablet-based touchscreen assessment/care planning tool; a medication adherence application; a SMS-based intervention to improve prevention.


125 Note: According to a June 2011 report, 32 states offer an online, publicly-accessible application for Medicaid and/or CHIP that could be submitted electronically while 18 states allow online renewals. Kaiser Commission on Medicaid and the Uninsured (2011, June). “Online Applications for Medicaid And/or CHIP: An Overview of Current Capabilities And Opportunities For Improvement” Retrieved from: http://www.kff.org/medicaid/upload/8203.pdf
diabetes education and care management; and remote monitoring of patients with COPD.

CTA Draft Paper: "mHealth Technologies: Applications to Benefit Older Adults

CTA Press Release about Grants

Ipad Used to Jump-Start Memory, Mobility, Social Skills at Florida Nursing Home

An article in the Montreal Gazette earlier this month focused on the Apple Ipad 2 tablet as a tool to help jump-start the memory and social activities of residents at a Florida Nursing home. The activity coordinator explains that residents who are unable to type or whose hands have atrophied can swipe their hands across the glass. The nursing home had previously tried using a Nintendo Wii to develop motor skills, but found that it was too cumbersome for people with mobility problems. Residents have begun using the I-Pad to play checkers, to sing along with music, and to play memory games. Two professors at Wake Forest University explain that they developed a Mobility Assessment Tool for the Ipad that shows animated figures doing tasks like walking and climbing stairs which have been helpful for senior citizens to picture themselves doing those tasks. Montreal Gazette: "iPad helps elderly remember, socialize"

Pilot Programs Could Promote Aging in Place, but Expense Is a Barrier

The Oregon Center for Aging & Technology at Oregon Health & Science University is conducting several studies to test new technologies to allow older people to age in their homes. One of the study participants, profiled by the Los Angeles Times has agreed to have her condominium outfitted, and it includes motion sensors to record her gait and walking speed, a door sensor that senses when she is leaving the house, and a refrigerator sensor to monitor her eating. She has also shared her home with a 4-foot tall robot that her relatives could control remotely and that includes a video monitor. A video game she plays on her computer monitors her results to detect any abnormalities.

The equipment in her home is monitored by researchers at the Oregon lab, which also has a model home to test new gadgets, including a bed with sensors that assess breathing patterns, heart rate, and sleep quality. Other technologies include an electronic pill box that monitors when medication is taken, and a Wii video game system that measures weight and balance. Future possibilities include software to assist people with dementia find their way home, devices that can interpret facial expressions to detect depression, and robotic "pets" for seniors. While the devices could prove helpful, expense is a large obstacle, including monthly monitoring bills, and a researcher acknowledged that technology could also allow people to become more isolated, though she also suggested that it could help caregivers focus on larger issues than whether or not somebody took their medicine.

Los Angeles Times "Elder care goes high tech"

Timeslips Interactive Website Launched

The Creative Storytelling Project recently launched a new website, Timeslips.org, that is intended to allow people with dementia and their caregivers to read, create, and share stories, based on hundreds of images and questions provided on the website. Visitors to the website are given pictures with prompting questions to start a conversation, and/or write a story to share with other visitors. Visitors can also read stories about the pictures on the site, for example, a picture of a baby sitting in a suitcase prompted the story called "Travelling Baby" about a boy named "Sam" (for Samsonite) who loved to travel. Timeslips

Technology: Good for Patients, Caregivers, and Doctors

An article in American Medical News focuses on how technology can enable family caregivers to be more involved in the care of their loved one. A pulmonologist interviewed for the article explains that when a patient brings a family caregiver to an appointment, he begins the conversation by discussing when and how he can share information with the caregiver. American Medical News: "How technology can connect doctors and caregivers"

Australia: Nursing Home Begins Using GPS Tracking Devices for Residents

A recent article in the Herald Sun profiled a nursing home in Melbourne that will begin fitting GPS tracking devices on elderly residents with dementia. The decision was made after a resident wandered and died. However, advocates cite minimum staffing ratios of one staff member per five children for childcare centers and suggest that mandating similar staffing ratios in nursing homes would be more helpful in preventing residents from wandering. According to Australian government data, 745 residents went missing in fiscal year 2009-10. The nursing home will offer families the option of having residents with dementia wear a wristband that will trigger an alarm if they approach a door. Herald Sun: "Aged care advocates angered at GPS plan for elderly"

Canada: Debate on GPS Tracking Devices

Earlier this year, the Montreal Police Department shelved a program to give GPS bracelet devices to elderly who are prone to wandering. The bracelets allow
family members to track the whereabouts of a loved one using GPS technology. While the proposal was shelved, the police department is now reconsidering after two elderly citizens went wandering in February, leading to extensive searches. In addition to this government program, the author also discusses a smart phone application that allows family members to log onto a website to see the most recent locations of the phone's owner. In order for all of these technologies to function properly, the wanderer must keep the device with them when they wander.

Montreal Gazette: New cellphone app lets 'watchers' track 'wanderers'
FCA Blog: "Baby Boomer Caregiver Use of Technologies and Social Media Increasing"

Colorado: Mother Sues City over Computer System Denying Prescription for Son
A Denver mother announced a lawsuit against the city and county of Denver over a benefit system malfunction which incorrectly told a Walgreens pharmacy that her son did not qualify for Medicaid in 2009. According to the Denver Post, despite having letters from the agency attesting to his eligibility, his mother couldn't get his asthma prescription filled for several months because the computer system indicated to the pharmacy that he was ineligible. Her son died in 2009 after complications from an asthma attack. Colorado's re-vamp of six separate benefit computer systems into one system began in 2002 and has been a rocky transition with lawsuits and settlements over backlogs, wrongful terminations, and incorrect eligibility determinations.

Denver Post: "Mom sues Denver, three workers over child's death"

Indiana's Privatization of Medicaid and Food Stamps Programs Falls Short
The Los Angeles Times profiled Indiana's negative experience with privatizing its Medicaid and Food Stamp programs. The state hired an IBM-led consortium of companies, including a company called ACS that has been heavily involved in providing outsourced services in other states. Under the privatized system, Medicaid and Food Stamp beneficiaries had to apply for benefits online or through call centers, instead of through caseworkers.

According to advocates, the transition led to disrupted benefits for recipients, and the Times profiles an 80-year woman whose Medicaid payments were cut off because she hadn't called into an eligibility hot line in 2008 on the same day she was hospitalized for congestive heart failure. The state's negative error rate (a measurement of how often cases are incorrectly closed or denied) was below the national average from 2001 to 2007, however, it more than doubled to over 13% one year after the firms took over - the largest rate increase in the nation. In October of 2009, Governor Mitch Daniels acknowledged that replacing caseworkers with centralized call centers "just didn't work," and canceled the 10-year contract with IBM, while giving ACS an eight-year contract worth $638 million. The state's lawsuit against IBM is slated to begin in February 2012, and the state cites problems in its lawsuit including lost documents, piled up cases, and workers routinely denying applications to reduce backlogs. Los Angeles Times: "Indiana's bumpy road to privatization"

Minnesota: Senior LinkAge Line Now Answers Questions Via Instant Messaging
The Star Tribune reports that Minnesota's information and referral service for older people and their families, which already answers over 119,000 calls for help every year, will begin using instant messaging to answer inquiries. The system will rely on the expertise of 45 experts from 10 state agencies and is expected to generate an additional 20,000 requests for help annually. The service is operated by six regional area agencies on aging and relies on 45 paid counselors, 300 trained volunteers, and is funded with $2.9 million in state and federal money. The executive director of the Minnesota Board on Aging explains that this new channel helps to make the program more of a "one-stop shop." Star Tribune: "Help line expands aid for seniors"

Oklahoma: First State to Automate Enrollment Decisions for Medicaid Online
Kaiser Health News profiled Oklahoma's new online enrollment Web Site for Medicaid and suggested that the process (11 minutes) was as quick as setting up a Netflix account. Oklahoma is the first state to fully automate enrollment- meaning people can apply online and receive a decision about whether or not they qualify for SoonerCare (OK's version of Medicaid) online. The move is important because of the approximately 16 million Americans who are slated to become eligible for Medicaid under the Affordable Care Act in 2014. The
state predicts that at least 250,000 Oklahomans will become new enrollees when the provision takes effect. Kaiser Health News notes the irony in Oklahoma's new capability at the same time that the state turned down a $54.5 million federal grant to develop its state health exchange. Kaiser Health News: "Making Medicaid As Easy As A Netflix Membership"

**Ontario Will Implement System to Find Missing Seniors**

Premier Dalton McGuinty announced in May that Ontario will create a province-wide system, similar to "Silver Alerts" used in the U.S. to help find missing seniors who suffer from Alzheimer's and other cognitive impairments. It is estimated that 180,000 Ontarians currently have some form of dementia and that number will grow to 250,000 by 2020. The program will be the first of its kind in Canada. *CBC News: "Ontario to set up system to find missing seniors"

**Research on Family Caregivers Outside of the U.S.**

**Australia’s 2.6 Million Caregivers: 68% are Women**

According to data from the Survey of Disability, Ageing and Carers, four million people reported having a disability in 2009. The rate of disability increased with age, for example, 88% of people aged 90 and over had a disability compared to 3.4% for people aged four years and younger. Twenty-nine percent of caregivers report that they are the primary caregiver, and two-thirds of caregivers were women. *Disability, Ageing and Carers, Australia: Summary of Findings, 2009*

**Australia: Report On 2.6 Million Australian Family Caregivers**

According to Australian government data, 29% of caregivers identified themselves as the primary caregiver, defined as the person providing the most assistance, and women were about twice as likely to fill this role (5% women, compared to 2% for men). One-third of caregivers reported having a disability themselves, as compared to 16% of non-caregivers who reported having a disability. Forty percent of primary caregivers were employed as compared to 66% of non-caregivers, and only nine percent of primary caregivers who cared for 40 hours a week were also able to work full time. Caregivers aged 15 years and older (49%) were more likely than non-caregivers (37%) to live in a household with income in the bottom two income quintiles, and 62% of primary caregivers were in the two bottom income quintiles. In terms of duration, 12% of primary caregivers had been caring for less than two years, 28% had been caring for two to four years, and 6% had been caring for 25 years or more. Of the 98,300 primary caregivers who reported a need for respite care, only 36% had ever used it. Forty percent of primary caregivers providing 40 hours or more of care (per week) were likely to frequently feel worried or depressed, as compared to 27% for caregivers who provide 20 hours or less of care. Twenty-five percent of primary caregivers reported losing touch with their existing friends, while 61% of caregivers with a spouse or partner (who isn't the care recipient) reported that the relationship had been affected. *The Australian: "Study highlights the pain of primary carers"

*Australian Bureau of Statistics: "Caring in the Community, Australia, 2009"*
Australia Focuses on Caregivers in Welfare Report
The tenth annual report from the Australian Institute of Health and Welfare was released in 2011 and chapter seven focuses on the 2.6 million family caregivers in Australia, of these caregivers, 45% were caring for a spouse. The authors cite data that found that over 25% of caregivers were "hidden" as defined by not seeking service providers. Thirty-eight percent of primary caregivers wanted an improvement or more support in their situation, with caregivers who had been caregiving for five years or more seeking more help. Financial assistance was the most commonly reported additional support wanted by caregivers.

AIHW: "Australia's welfare 2011"

Australia: Report on Transition Care Program
Australia's Institute of Health and Welfare released a report on its Transition Care Program (TCP) activities from July 2008 to June 2009. The program provides care to older Australians for up to 12 weeks immediately after their hospital discharge (in their home or in a care facility) with the goal of improving independence and also providing time to consider long-term care arrangements. The program served 12,600 people during 2008/09 and improved their independence from an average score of 76 at the beginning of treatment to a score of 90 at the end (as measured by the Modified Barthel index score). After receiving TCP, half of the recipients returned to the community (35% supported with a community aged care service and 15% with no services), while 19% transferred to residential care, and 22% returned to the hospital. The average length of TCP per participant was seven weeks. AIHW: "Older people leaving hospital: a statistical overview of the Transition Care Program in 2008-09"

Canada: Survey Finds One Sibling Does Majority of Caregiving Work
In a 2011 survey of 383 Canadian caregivers, 41% of caregivers reported that one sibling took all or most of the responsibility for caregiving for parent(s) who needed assistance. The authors titled their summary report the "50-50 Rule," referring to age 50 as the average age when people will find themselves becoming caregivers and the other 50 referring to the need to split caregiving responsibilities with family members. The report provides seven examples of real-life family caregiver/sibling situations with advice on how to address the issues. Primary caregivers in the survey report spending 14 hours a week providing care.

Home Instead Senior Care: "The 50-50 Rule: Helping Siblings Overcome Family Conflict While Caring for Aging Parents"

Canada: Gray Tsunami or "Apocalyptic Demography?"
An October 2011 report examines the current state of long-term care in Canada, with a focus on family caregivers and the estimated $25 billion in "free" care they provide every year. The authors explain that Canada's current system assumes a large amount of family caregiving is available and views the health care system as more of a safety net when family care isn't available or sufficient. While the authors caution that the shifting demographics and higher health care use for older Canadians can be over-blown (labeled as Apocalyptic Demography), they suggest that Canada does need to have a national, transparent conversation about home health care, with a greater focus on the needs of family caregivers as part of the long-term care system. Two possibilities are enacting legislation related specifically to long-term community care, or adding long-term community care to Canada's medicare program. They conclude: "Despite the many calls for the federal government to take a leadership role in establishing formal support for caregivers, to date help has not been forthcoming."

IRPP: "Population Aging and the Evolving Care Needs of Older Canadians"
Montreal Gazette: "Caregiver shortage 'major cause of concern'"

Europe: Job Quality Effects on Employment, Social Activities, and Caregiving
A report uses data on employed Europeans aged 50-65 to estimate the effect of job quality on participation in the labor market, social activities, and caregiving. Similar to past research, their model finds that women are more likely to be caregivers, and the model also finds that age had a negative impact on whether or not a person is employed. While the model finds that the necessity to provide care did not appear to be a factor of people leaving jobs early, being employed full-time did reduce the chance of being a caregiver. The authors note that this may not account for the possibility of shared obligations within families, financial transfers, access to formal care, and the possibility of work/family arrangements. In addition, while this study is focused on employed seniors, "the burden of informal care is to a large extent carried by inactive and unemployed females of this generation." Participating in social activities increased the likelihood of being a caregiver, and the authors suggest that the positive rewards people receive from social activities may make them more likely to be a caregiver to members of their club, association, or network. Centre d'Economie de la Sorbonne: "The social economy of ageing : Job quality and pathways beyond the labour market in Europe"
Europe: Caregiving Decision Making for Only Children vs. Siblings in 12 Countries
A discussion paper from the Institute of Labor analyzed the decision making process for adult children to provide caregiving to a parent and analyzed differences between only children and children with siblings. Using data from 12 European countries on adult children who are 40 years or older, the authors’ models find that generally speaking, only children are more involved in informal caregiving than children with siblings and that they also provide more hours of care. Sibling decision-making about caregiving is classified as cooperative or noncooperative and the authors find that 71% of the siblings fit better into the noncooperative model. The non-cooperativeness is, on average, 10.5% higher for brother-brother dyads compared to sister-sister dyads, while brother-sister dyads are more cooperative than brother-brother dyads. Siblings who are more highly educated were less likely to provide informal care, possibly due to different value sets or competing interests.
IZA: "The Effects of Cooperation: A Structural Model of Siblings’ Caregiving Interactions"

French Caregivers: Marjoiaty are Women, but Men may Begin to Play Larger Role
A November 2011 policy brief focuses on family caregivers in France and the fact that the majority of caregivers are women. The authors explain that demographics and retirement ages are changing, and speculate that French men may or professional caregivers may need to play a larger role in caregiving in the future.
Elder Care and Dependence: no longer just a women’s concern?

Ireland: Experiences of Former Family Carers
A 2011 report focused on the needs and experiences of former carers (family caregivers) in Ireland. Former carers are people whose loved one has moved into a care facility or whose loved one has passed away. The authors conducted a focus group with 14 former formercarers and 26 one-on-one interviews with former carers. The carers explained that they had left their pre-caring worlds to become carers, but this "world" also ended when their loved one moved away or passed on. Carers explained that the transition to a third, post-carer world was difficult, and some cited the end of receiving a carer allowance as making them feel devalued by the government. Carers also mentioned that they wanted to share the knowledge they had gained as a carer with others. The authors explain that while males represent 40% of the carers in Ireland, support groups are made up predominantly of women and the government may want to consider options to support male carers. Liam O’Sullivan, the Executive Director of Care Alliance Ireland, wrote a blog posting as part of FCA’s “30 Days of Caregiving.”
Care Alliance Ireland: "Between Worlds: The Experiences and Needs of Former Family Carers"

Life After Care: “A handbook to support transition to post-caring”

Day 23: Life After Caregiving – Ireland’s Experience

Ireland: Report on the Elderly and Loneliness
The Society of St. Vincent de Paul in Ireland released a report that examined attitudes of older people and found that loneliness was one of the largest issues for the elderly. The authors explain that loneliness may be due to isolation, especially in rural areas, where reductions in post offices and transportation options may contribute to less human contact and also reduce access to hospitals and other medical services. The report is based on interviews with almost 600 elders throughout Ireland.
Society of St Vincent de Paul "Older People-Experiences and Issues"

Italy Relies on Mostly Immigrant Workforce for Caregiving
A report analyzes the direct care workforce in Italy through interviews with direct care workers. The authors explain that the public provision of caregiving is fairly limited, and while women had historically served as family caregivers, the changing economy means that fewer women are taking on this role. As a result, the main "pillar" of social care (not medical) for the elderly are the estimated 780,000 Personal Assistants (badanti), who are personally recruited by the family of the care recipient and are hired on an informal basis. It is estimated that 90% of the badanti are foreign workers. The cost of hiring a personal assistant in the underground market is 30-40% less than going through the regular market channels. The personal assistants who were interviewed preferred being directly hired by a family (rather than through a publicly-funded program) because the publicly-funded programs include a Individual Care Plan which specifies few and limited hours of assistance. In addition, there are means tests to qualify for publicly-funded care, meaning the recipient lives in poor social and housing conditions, as compared to working in a private household that has the financial ability to hire direct workers.
WALQING: "Once there were wives and daughters, now there are badanti"
Spain: Dysfunctional Families Worsen Caregiver Strain
A comparative study of the demands of caregiving analyzes two sub-groups, those who master and overcome the difficult tasks associated with caring, and those who find themselves impaired due to caregiving responsibilities. The authors analyzed the relationship between the functionality of the family and the quality of life (QoL) of caregivers of dependent relatives. The study included 153 caregivers from two different hospital settings in the city of Salamanca, Spain. Caregiver variables were demographic characteristics, care recipient profile, and family functionality perceived by the caregiver. To study the influence of the family function questionnaire on quality of life, researchers applied the Canonical Correspondence Analysis (CCA). Researchers found the strongest relationship between the caregiver's quality of life (as measured by their physical and mental well-being) and family functionality. The authors conclude: "The results of this study suggest that those caregivers who make important decisions together with their family are the ones who feel a better state of physical and mental well-being.”

BioMed Central: “Relationships between quality of life and family function in caregiver”

Thailand: Study Examines Intergenerational Family Care
A March 2011 study examined the role of adult children in providing care for elderly family members in Thailand and also examined the grandparents and their role in providing care for their grandchildren. The authors explain that the family is the most important part of the four pronged "care diamond" that includes the government, market, and voluntary sector. However, reduced fertility and increased migration are both contributing to a reduction in co-residence of elderly parents with their adult children and this has important implications for the future provision of elder care.

University of Michigan Population Studies Center: "Intergenerational Family Care for and by Older People in Thailand”

UK: Flexible Working Conditions in UK Facilitate Caregiving
A survey of 1,600 workplaces in Britain that included a random sampling of up to 25 employees in each workplace finds two flexible working practices are most associated with employees providing informal care. Flextime and the ability to reduce working hours were associated with about 10% more hours of informal care for both men and women. The ability to reduce working hours appeared to facilitate care mostly among full-time workers, while flextime seemed to help with small amounts of care, but did not affect employees who were providing intensive caregiving. Institute for Social and Economic Research University of Essex “Access to Flexible Working and Informal Care”

Focus on International Support for Family Caregivers

Canada: Caregiver Makes Case for Timely Geriatric Assessments
A recent article in the Globe and Mail from a family caregiver argues that timely geriatric assessments would be better for older patients and their caregivers. Corinne LaBossiere explains that she and her husband recently moved their 90 year old aunt, “Aunty B” with dementia to live closer to them so they could assist with her care. While the transition went smoothly at first, Aunty B soon became frustrated and confused with her new surroundings, leading her doctors to adjust the dosage of her anti-anxiety medication. While the caregivers asked for an assessment of their aunt, they were told about a six-month waiting list for assessments. Three weeks after moving in, Aunty B tried to leave and threatened to throw a vase at a staff member. Later that night at the hospital, a doctor informed them that she had a urinary tract infection, prescribed some medicines, and released her. Aunty B’s behavior problems continued, and a second trip to the hospital ensued, where a doctor found a second "source" for the delirium and said he’d release her. In response, LaBossiere and her husband successfully advocated for a psychiatric assessment that led to a successful rebalancing of medications. LaBossiere concludes: "It makes you wonder: With our aging population and a rising tide of seniors with dementia, wouldn't timely assessments by geriatricians be a more effective, less costly, less traumatizing form of care than police, paramedics and hospital emergency rooms?”

Globe and Mail: “Our aunt tried to flee her seniors residence”

Canada Politicians Promise $300 Caregiver Tax Credit in Proposed Budgets
Canadian politicians introduced competing budget proposals, both with positive policy changes for family caregivers. Liberal Leader Michael Ignatieff proposed a $1 billion program that would provide a new, six-month family care employment insurance program for the approximately 30,000 Canadians who take time off of work to serve as caregivers for sick family members, as well as a $1,350 family care benefit. In contrast, Canada's Conservative Party proposed a $300 tax credit for family caregivers in its budget and estimates that 500,000 people would use the credit, for a cost of $160 million a year. Health Minister Deb Matthews pledged
Canada: Ontario Hiring 700 Health-Care Workers for Aggressive Dementia Patients
The Health Ministry of Ontario announced plans to hire 700 new health-care workers as part of a new program, the Ontario Behavioural Support Systems Project, which will begin with four pilot projects and be rolled out across Ontario within a year. One of the designers of the program explains its three pronged approach includes better coordination of existing services, deploying teams of specialists who can assess behavourial problems and educate health-care workers already in the field, and to identifying gaps in services and finding "flexible" solutions. The goal is to allow more people to stay in their homes and also to reduce the use of medication and restraints for patients who are already living in institutions. A doctor interviewed in the article was cautiously optimistic, noting that in some cases, even if a person is trained to understand behaviours caused by the disease, there isn't much people can do. She also suggested that there is little dementia training available and it may be difficult to find 700 qualified people. The Globe and Mail: "Ontario to expand help for aggressive dementia patients"

Ireland: Respite Service Cuts Stretch Family Caregivers
Dr. Karena Meehan presented on the impact of recent cutbacks to home help services and respite beds for the approximately 40,000 people with dementia in Ireland. She explained to the Irish Times: "All home help services have been cut back enormously and we are now finding it very difficult to get support for people with dementia unless they have physical needs....Some of the first beds to have been slashed were respite beds and without this care, people caring for loved ones with dementia are being stretched to the limit in terms of being able to cope." The National Alzheimer's Association and Western Alzheimer's Foundation have provided grants to families that allow for small respite breaks and the Minister of Health for Ireland also recently released results from a longitudinal study of 8,000 Irish people aged 50 and older. One finding highlights the extensive role of family caregivers:
"People with disabilities receive an average of 118 hours of help per month. As the most common primary helper for this group is the care recipient's spouse, this translates into extensive inputs by older adults into the care of other older adults."

Ireland Times: "Dementia home carers 'stretched to the limit'"

"Fifty Plus in Ireland 2011. First Results from the Irish Longitudinal Study on Ageing"

Scotland: Government Considers Reducing Free Personal Care for Elderly
The Scottish Government considered reducing or changing its free personal and nursing care program for people aged 65 and older. The benefit was started in 2002, however, costs have nearly doubled since the program began. One possible strategy is to end universal entitlement and concentrate on services for the poorest 20% of society. Another option includes only providing five hours of home care per week at no cost and requiring any additional hours to be paid for by the care recipient. The Scotsman: "Free care for Scots elderly is set to be axed"

UK: Report Suggests National Standards for Social Care System
The Law Commission in the United Kingdom released a report in May 2011 calling for an overhaul to the system of social supports and services provided in England and Wales, including creating a legal duty on local councils to protect vulnerable adults from abuse, providing grants for individuals to spend on care homes, and additional support for family caregivers of the elderly. Advocates have suggested in the past that elderly people have had to resort to legal avenues in order to access needed services because local councils are uneven in the level of support provided. While the report does not suggest eligibility frameworks, it does suggest that laws must be clearer about basic entitlements to services and must be consistently applied across local councils. The report also suggests introducing more elements of consumer direction, by letting the care recipient choose for themselves how to spend a "personal budget" on a residential home of their choice. A research brief, also recently released, focuses on policy options for financing of long-term care in the U.K.
Law Commission "Adult Social Care"
Telegraph: "Law Commission: elderly care must be reformed"
International Longevity Center- UK: "Past Caring? Widening the Debate on Funding Long-Term Care"

UK Government Report on Adult Social Care
The UK Care Quality Commission released its third annual "State of Care" report that provides data on health and social care. There were 4,608 care homes with nursing as of July 2011, and caring for older people and people with dementia is the most common type of care provided. Approximately 45% of care home residents...
are self-funding their stays (as compared to the government paying). Thirteen percent of adults and carers who received council-funded social care were able to self-direct in 2009/10. The authors suggest that "the reduction in social care budgets and increased demand is resulting in local authorities tightening their eligibility criteria for people to receive state-funded community care." UK Care Quality Commission: "State of Care 2010/11"

UK: Report Measures Unmet Need for Long-Term Care

A report from the Office for National Statistics demonstrates the difficulty that researchers often face in analyzing data about long-term care and measuring need for these services. Expenditures on adults aged 65 or older increased 8.2% between 2003-04 and 2008-09, though the cost of providing services increased even more dramatically during the same time frame, with a 14.2% increase for residential care and 26% increase for home care. The authors use three data sets and find that there is significant unmet need for services, ranging from 15-61%. In addition, they cite a simulation that attempted to measure unmet need if funding increased only enough to maintain current levels of care and also a simulation of a 6.7% budget cut. When family caregivers are removed from this equation, the hours of unmet need more than doubles from 62 million hours to 143 million hours (if funding levels increase to maintain current levels of care). If the budget is reduced, and family caregivers are taken out of the equation, the hours of unmet care increases from 118 million hours to 231 million hours of unmet care.

Office for National Statistics: "Measuring unmet need for social care amongst older people"

Advanced Planning for End-of-Life Care

Planning for end-of-life care continued to be a focus on both scholarly research and of media coverage about the difficult situations faced by family members when they are unsure of their loved one’s desires around end-of-life care. The Obama administration reversed course on a policy and announced in January that Medicare would not pay for discussions about advanced care planning as part of the annual Medicare wellness visit. Advanced care planning can include creating an advanced directive which allows a patient to communicate his or her health care preferences if they become unable to make these decisions for themselves.

Tools to Plan End-of-Life Care Preferences
The Wall Street Journal focused on tools for people to direct what type of care they want to receive at the end-of-life. One program highlighted is the Physician Orders for Life-Sustaining Treatment (Polst), currently used in 14 states while an additional 16 states are developing programs. Polst programs provide paperwork that meet local regulations and also train health-care providers who will discuss end-of-life treatment choices with patients with terminal illnesses or people who would like to define their care preferences.

In contrast to an advance directive, the Polst form spells out specific treatment instructions and becomes part of a patient’s medical record. Bernard Hammes, chairman of a national task force that develops Polst programs designed a training program called Respecting Choices that has been duplicated throughout the U.S. and internationally. Designed for nurses, social workers, and chaplains at the Gunderson Lutheran Health System in Wisconsin, the program teaches them how to facilitate and document advance care planning conversations with patients and families.
Aetna, a health insurance company, began using nurse-care managers in 2004 to work with patients and their families to ensure that advanced directives are in place and followed, and this has correlated with increased utilization of hospice care and reduced health care costs. Randall Krakauer, Aetna's head of Medicare medical management, explains that the insurer does not try to suggest specific end-of-life choices, but when advanced cared preferences are not known, "by default we end up using very aggressive curative therapy which in most cases is not only inappropriate, but would not be the patient's choice."

National Healthcare Decisions Day

Wall Street Journal: "New Efforts to Simplify End-of-Life Care Wishes"

FCA Fact Sheet: "End-of-Life Choices: Holding on and Letting Go"

Issues with Advanced Directives that can Prevent Preferences from Being Followed

A study in the January issue of Annals of Internal Medicine (Volume 154, Number 2), analyzed legal issues with Advanced Directives that may prevent a patient's preferences from being followed. Some of the issues include poor readability (all laws were written above a 12th grade reading level) and restrictions on health care agent or surrogate restrictions (40 states don't include same-sex or domestic partners as default surrogates). Another study by the CDC found that care recipients under age 65 were less likely to have any advanced directives than recipients aged 85 and over and that the most common type of advanced directives were living wills and do not resuscitate orders.


Annals of Internal Medicine: "Lost in Translation: The Unintended Consequences of Advance Directive Law on Clinical Care"

CDC: "Use of Advance Directives in Long-term Care Populations"

Importance of Communication between Adult Children and their Parents

A Sacramento Bee article addresses the importance of communication between adult children and their parents around long-term care issues, including end-of-life health care preferences and finances. Barbara Gillogly, a gerontology professor, explains that while conversations are awkward, "If people won't talk about it, they need to understand that at some point, somebody else will make those decisions for them... Do you want the state to make those decisions? Do you want your adult children to make their best guess? Or do you want them to know?"

Sacramento Bee: "Never too early to discuss end-of-life issues with parents"

ASCO Focuses on Palliative Care and Planning for Advanced Cancer Care

The American Society of Clinical Oncology (ASCO) released a new policy statement in January, encouraging doctors to initiate discussions about the full range of palliative care and treatment options soon after patients' diagnosis with advanced cancer. At a recent policy forum, the CEO of ASCO, Allen S. Lichter, MD, explained the need for oncologists to start conversations about palliative care, especially since a recent poll found that doctors and providers are the most trusted source of information. In an article about the new policy statement, a nurse at a West Palm Beach hospital, who serves as an oncology patient navigator, explains that "People need to know not to be afraid of talking about it. I have never, ever, ever had a family say to me that we did this too soon. I have had families say I wish we did this sooner." ASCO has released a guide for patients and intends to release more detailed guidelines for doctors later this year.

ASCO: "Advanced Cancer Care Planning"

The Palm Beach Post: "New guidelines urge doctors to start end-of-life discussions sooner."

National Journal and Regence Foundation Policy Forum Recording: Living Well at the End of Life

Report Provides Update on POLST Programs

AARP’s Public Policy Institute released a report that provides an update on the implementation and adoption of Physician Orders for Life-Sustaining Treatment (POLST) programs in states. The POLST protocol requires a health care professional to discuss available treatment options with seriously ill patients (or their surrogates), and these preferences are then documented on a standardized medical form that the patient keeps with them. POLST programs have been adopted by 10 states by the beginning of 2010 with other states also developing programs.
The study examines the experience of 12 states to identify factors that helped or hindered both adoption and meaningful implementation of the program. Well-established statewide end-of-life coalitions or palliative care organizations were helpful with starting POLST development, and a core group of "physician champions" is important to gaining acceptance by health care institutions. POLST proponents identified 40 issues and barriers during implementation, including what elements should be included in the form, decision-making authority for surrogates when a patient lacks decision-making ability, and training and education of doctors both in communication skills for the POLST conversations and the therapeutic impact of interventions like CPR and tube feeding for older chronic care patients. AARP PPI: Improving Advanced Illness Care: The Evolution of State POLST Programs

Center for Ethics in Health Care, Oregon Health & Sciences University. POLST Web Site

Massachusetts: State Panel on End-Of-Life Care Releases Report
In 2009, the Massachusetts legislature assigned a panel of experts to "identify best practices for end-of-life care" and "present recommendations for legislative, regulatory, or other policy changes..." The panel released its report on March 14, 2011 and it includes a number of recommendations to improve end-of-life care. The panel's report suggest that the state's health care system does an inadequate job in learning about, documenting, and following patients' wishes around end-of-life care. The authors note that while 70% of Americans would prefer to die at home, in Massachusetts, over 70% of people die in hospitals or nursing homes. The panel's recommendations include implementing a high-visibility public awareness campaign, requiring end-of-life care education in state-financed medical, nursing, and social work programs, and requiring all health insures in Massachusetts to cover hospice care.
*The Patriot Ledger: "End-of-life care in Massachusetts needs improvement, panel says"

Massachusetts Expert Panel on End of Life Care Final Report - Patient Centered Care and Human Mortality

Minnesota: Twin Cities Adopt Wisconsin's Advanced Health Care Directives Effort
A highly successful initiative in La Crosse, Wisconsin to increase the number of people completing advanced health care directives is now being duplicated in the Twin Cities in Minnesota and is called "Honoring Choices Minnesota." The program is three years old and includes every health provider and health system in the metro area. In La Crosse, more than 90% of adults who die have filled out a living will, the highest rate of any city in the U.S. In the Minneapolis-based Allina Hospitals, the number of patients filling out advanced care directives has more than doubled as a result of the program, from 16% to 39%.
*Minnesota Public Radio "Twin Cities program helps patients discuss end-of-life planning"

FCA Fact Sheet: "End-of-Life Decision Making"

Missouri: Legislation Would Allow Family Members to Make Health Care Decisions
Forty-four states currently have "family consent" laws that allow family members to make health care decisions on behalf of a family member. A Missouri state representative introduced legislation this year to also allow Missourians to make health care decisions for a family member. Under the introduced legislation, if a person is ill and doesn't have an advanced directive, the bill would establish a default order of family members who could make decisions. Critics of the bill suggest that family members may not have the best interests of the patient in mind, while a hospital social worker from St. Louis was concerned that domestic partners were excluded from the bill. The representative plans to reintroduce the legislation in January 2012.
*KCUR: "End-of-Life Decisions: Family Consent Law Proposed"

New York: Family Caregiver Advocates for Advanced Health Care Proxy Legislation
A recent blog posting on The New Old Age discussed one family caregiver's challenge in navigating the health care system on behalf of her mother and her potential solution- an advanced health care proxy. DonaaAppell is a registered nurse and is also the primary caregiver for her mother. Appell cited a phone call in which her mother's mail order pharmacy refused to speak with her without her mother's permission as the inspiration for a law she has been trying to have enacted in New York State for three years. Advanced health directives only take effect when the person becomes incapacitated, thus limiting their effectiveness for caregivers like Appell whose mother has capacity. The advanced health care proxy would allow a patient to designate a friend, family member or a doctor to assist with health care decisions even when the patient is still legally competent. Maine, Maryland, New Mexico and Wisconsin have similar laws that allow agents to take over for the patient when they become incapacitated or sooner if specified in the document and North Dakota and Vermont both allow advance directives to become effective while the patient is capable. *New York Times This New Old Age: "A Better Way to Help with Medical Decisions"
See Also:
EurakAlert: “Clinicians’ attention lacking in discussions of end-of-life care” (May 2011)
EurakAlert: “Computer program aids patients in end-of-life planning” (May, 2011)
EurakAlert: “Pitt study: End-of-life decisions take longer if patient hasn’t shared wishes with family” (January 2011)
OregonLive.com: “At the end of life, Oregon and Washington residents want less medical intervention” (July 2011)

Palliative and Hospice Care

Research focused in 2011 on how palliative or hospice care can improve quality of life and also examined differences in the type of care received and the difference in healthcare expenditures for people enrolled in hospice or palliative care. There was a growing focus on the growth in hospice care and whether or not for-profit companies are “selecting” the most profitable patients. The Affordable Care Act includes a three-year demonstration program at 15 sites nationwide where Medicare will cover both curative and hospice care (under current Medicare rules, a person must cease curative care in order to receive hospice care).

Eleanor Clift: "Hospice and the End Game"

Eleanor Clift, a veteran reporter for Newsweek and a panelist on the McLaughlin Group, provides a poignant account of hospice care for her husband who passed away from cancer in 2005. Their experience, featured in the August issue of Health Affairs, connects the personally difficult decisions around end-of-life care with the policy issues—e.g., the uproar over the Affordable Care Act’s inclusion of compensating a doctor to have a discussion about a patient’s preferences for end-of-life care. She explains that Senator Johnny Isakson (R-GA) who introduced the provision couldn’t understand how an individual stating their end-of-life care preferences was somehow transformed into “death panels.” She concludes: “There are those who every day—like my husband, Tom—receive terminal diagnoses and display great courage, surprising their family and friends, and perhaps even themselves. It’s not unique to the human experience, and as people enter this last stage of life, they deserve the knowledge to make the choices that are right for them.” Health Affairs: "Hospice and the End Game" (article is free)

Spending for Hospice Care for Nursing Home Residents Has Increased 70% since 2005

A July report from the Inspector General at Health and Human Services examines the growth in hospice care in nursing facilities and suggests that “Some hospices may be seeking beneficiaries with particular characteristics, including those with conditions associated with longer but less complex care.” The report recommends that CMS monitor hospices that depend heavily on nursing facility residents and to modify the payment system for hospice care in nursing facilities. CMS concurred with both recommendations and with the suggestion that the current payment structure may incentivize hospices to seek out beneficiaries in nursing facilities who “often receive longer but less complex care.” USA Today noted that the two largest for-profit hospice companies, Vitas and Gentiva, have spent $1.1 million on lobbying thus far this year, with a focus on a bill by Senator Ron Wyden (D-OR) that would require CMS to test a new payment system for two years. Medpac, which advises Congress on Medicare issues, expressed concerns in its March report on Medicare about the increase in longer hospice durations (suggesting that some patients may not meet the six month rule) and potential conflicts of interest between some nursing facilities and hospices.

Office of Inspector General: "Medicare Hospices That Focus on Nursing Facility Residents"

USA Today: "Hospice lobbyists battle over Medicare payment system"

Medpac: "Report to the Congress: Medicare Payment Policy" (Chapter 11: Hospice)

HealthAGEnDa Blog Addresses Potential Fraud in Hospice Use

Two recent posts on the healthAGEnDa blog analyzed recent media attention to hospices and whether or not fraud is a growing problem in Medicare funded hospice use. Chris Langston provides a brief primer on hospices, for example, 90% of hospice care is not delivered at a hospice, rather, services are delivered at home (55%), a nursing home (26%), or a hospital (10%). Over 80% of hospice clients are over 65, thus Medicare is a large funder, but Medicare regulations require patients to forgo curative treatment and their doctor must certify that they have six months or less to live. Langston explains that there isn’t much data on quality of care in...
hospices, but that the median number of days people receive hospice care is only 16. Only 37% of people who received hospice care in 2007 received 30 or more days of service. Referencing the overuse of hospice leading to rising costs, he suggests that the overall increase of Medicare beneficiaries receiving hospice care is a good thing (23% received hospice care in 2000, while it increased to 40% in 2008), and may actually be less costly than other healthcare. The second cost driver is length-of-stay, and while most stays are too short to truly benefit from hospice, there has been growth in a small number of people receiving hospice for long periods of time, especially at for-profit agencies, and for conditions like Alzheimer's disease. In his second post, Langston suggests lengthening the expected life requirement to nine months and highlights a demonstration in the Affordable Care Act that will allow people to receive curative and hospice care simultaneously.

HealthAGEnda: "Throwing the Baby Out With the Bathwater?"

Connecticut: Proposed Hospice Regulations Create Controversy

The state of Connecticut is considering regulatory changes for inpatient hospice facilities that would change requirements around medical staffing levels, onsite pharmacy services, spiritual counseling and building requirements. The draft changes were initiated during former Governor Rell's administration and are considered to be "financially devastating" and "could compromise patient care" by a hospice located in Branford, Connecticut, known as Connecticut Hospice. The medical director at Connecticut Hospice suggested that the proposed changes would essentially revoke the facility's unique designation as a palliative care hospital, a designation that allows it to receive higher rates under Medicare, Medicaid and private insurance. He also suggested that other providers may not be equipped to provide care for some hospice patients who may become agitated and predicted that this could lead to patients "ending up in emergency rooms." The executive director of another hospice in Connecticut suggested that 29 of the state's 30 hospices support the change and that families would benefit from having more inpatient hospice options located closer to their homes.

The Republic: "Proposed changes to Conn. hospice regulations pit end-of-life programs against one another"

Research on End-Of-Life Care and Spirituality

A recent analysis reviewed research on end-of-life care and spirituality as part of the United Kingdom's End of Life Care Strategy. The authors identified 248 studies that were classified and reviewed by three consultation groups. Five overarching themes were identified, including disciplinary and professional contexts (what sources the disciplines came from); concepts and definitions; spiritual assessment; spiritual interventions; and education and training. The authors provide ten recommendations and also conclude that while the review found a substantial amount of literature relevant to spiritual care at the end of life, there is less material addressing spiritual care in the context of end-of-life care.

Dept. of Health: "Spiritual Care at the End of Life: A systematic review of the literature"

Hospice Worker Produces Film on End-Of-Life Questions, Will Air on PBS

The New Old Age Blog recently profiled two friends who produced a movie entitled "Consider the Conversation: A Documentary on a Taboo Subject" that addresses end-of-life questions. Michael Bernhagen, one of the producers, started working at a hospice after his mother passed away with advanced vascular dementia without any doctors suggesting hospice care for his mother. In the movie, Bernhagen interviews 40 patients, chaplains, ministers, doctors, nurses, authors, and researchers. His friend, Terry Kaldhusdal, did the camera work and is a fourth-grade teacher whose brother passed away of pancreatic cancer at the age of 53. The two friends made the movie on a budget of $43,000 and a year of their unpaid work. It has already aired on West Virginia, California, Colorado, Illinois, Michigan and New Hampshire public television and is scheduled to air in additional states during the summer and fall.

The New Old Age: "End-of-life Care: A Portrait"

Consider the Conversation Web Site & PBS Schedule

Canada: Extensive Report on Hospice Care Released

The Parliamentary Committee on Palliative and Compassionate Care released a report in November that focuses on hospice and palliative care in Canada. The report is focused on four areas, including palliative and end-of-life care, suicide prevention, elder abuse, and a disability perspective on health care and community living. The authors note that only 16-30% of Canadians who need palliative care actually receive it, and also suggest that too many elders from the First Nation communities die in facilities far from their own homes. Family caregivers are recognized in the report for providing 70-80% of long-term care in Canada, at an estimated annual value of $25 billion.

PCPCC: Not to be Forgotten: Care of Vulnerable Canadians
United Kingdom: Campaign to Display Patient Charter on End of Life Care
The Royal College of General Practitioners and the Royal College of Nursing recently created a patient charter that contains seven "pledges" intended to make the last few weeks of a person's life as comfortable as possible. The organizations explain that general practitioners are often well-situated to facilitate conversations about end-of-life care and to ensure that patient's wishes are followed. A copy of the one-page charter will be sent to 8,500 General Practitioner offices in England for display in waiting rooms. *Independent: "End-of-life patient charter is unveiled"
RCGP and RCN: End of Life Care Patient Charter

United Kingdom: U.S. Could Learn from UK's Plan to Improve End-of-Life Care
A research brief from the Commonwealth Fund provides insight into England’s End Of Life Care Strategy, a ten year plan that was adopted in 2008 by the Department of Health and National Health Service. The brief explains that the U.S. and U.K. face some similar challenges in providing care and the author suggests that U.S. policymakers could learn from the U.K.’s experience. For example, the medical societies and caregiver organizations in the U.K. accept and support the plan, probably due to the participatory process in which the strategy was developed, which spanned two years and included an advisory board, six working groups, and consultations with 300 stakeholders. The English approach also focuses strongly on assisting physicians in recognizing when patients are entering a trajectory that may end in death, implementing care based on this, and using the metric of "death at home" (where most people prefer to die). The author explains, "However, the English approach that the government should try to increase awareness of the need for end-of-life care planning contrasts strongly with the situation in the United States, where the idea of compensating physicians for having end-of-life care conversations with their patients prompted fears, however unfounded, of the creation of "death panels" that would determine who deserved to live." *Commonwealth Fund: "England's Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices"

See Also:

* Consumer Day: “Special Talk Therapy Seems to Help Dying Patients 'Dignity therapy' can enhance their quality of life and their dignity, study finds” (July 2011)

* EurkAlert: “Hospice improves care for dementia patients and their families” (July 2011)

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Health Affairs: “Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries” (March 2011)

Kaiser Health News: “New Emergency Care Programs Focus On Quality-Of-Life Issues” (July 2011)

New York Times: “Looking for a Place to Die” (December 2011)

NPR: “Twelve Breaths: Lessons From The End Of Life” (July 2011)

NPR Shots Blog: “Hospice Companies Zero In On Nursing Home Patients” (July 2011)

Politico: “Medicare eyes hospice savings” (October 2011)

Reuters: “Are for-profit hospices cherry-picking patients?” (February 2011)

Reuters: “Many surgeons don't discuss end-of-life care: study” (December 2011)

The Australian: “Experts in palliative care welcome call for end-of-life changes” (January 2011)

The Globe and Mail: “There’s no manual for home death” (January 2011)

University of Michigan Health: “Supply of hospice services strongly associated with local area's median household income” (May 2011)

Preparing for Shifting Demographics in the U.S.

Researchers continued to analyze the extent to which city, state, and federal governments are prepared to not only provide services for the rapidly increasing population of seniors, but also to pay for these services.

Updated Statistics on Older Americans
A report produced by the Federal Interagency Forum on Aging-Related Statistics provides data on the status of the US population aged 65 and older. The report
includes 37 indicators, grouped into five sections, including population, economics, health status, health risks and behaviors, and health care. The older population in the US is expected to double from an estimated 35 million aged 65 and older in 2000 to 72 million in 2030, which will be almost 20% of the US population. The percentage of people aged 65 and over who are obese increased since 1988-1994 from 22% to 32% of the population in 2007-2008. Health care costs for older Americans experienced a dramatic upsurge, from $9,224 in 1992 to $15,081 in 2006. Increased health care costs also drove out-of-pocket spending for health care, which grew from 12% in 1977 to 28% in 2006. Federal Interagency Forum on Aging-Related Statistics: "Older Americans 2010: Key Indicators of Well-Being"

**CDC Releases Data Snapshot: ADL’s For People Aged 80 And Older**
The Center for Disease Control Morbidity and Mortality Weekly Report recently featured data on the percentages of people aged 80 and older who need assistance with activities of daily living (ADL's). Women were more likely than men to need assistance with personal care activities (14.8% vs. 10.2%). Of these activities, women were more likely than men to need assistance with bathing/showering (12.1% vs. 8.1%), dressing (9.1% vs. 7%), and eating (3.9% vs. 2.4%). The estimates are based on household interviews from a sample of the non-institutionalized U.S. population, and therefore excludes adults living in assisted living facilities, nursing homes for the elderly, hospitals for the chronically ill, or correctional facilities. *CDC: "QuickStats: Percentage of Noninstitutionalized Adults Aged ≥80 Years Who Need Help with Personal Care, by Sex --- United States, 2008-2009"

**2010 Census: Largest Increase in People Aged 65; More Older Males than Females**
A Census brief released in November provided data on the growth of the number of Americans aged 65 and older. The authors note that the 2010 Census found more people aged 65 years and older than in any previous census. The population of people aged 65 and older increased from 2000 to 2010 at a rate of 15.1%, which is larger than the total U.S. population growth of 9.7%. Males had a more rapid growth in the older population than females, and the largest growth rate was for males aged 85-94 years old (46.5%). Females in the same age group increased 22.9%. The largest growth for women was for females aged 65 to 69 years old at 28.2%. *U.S. Census: The Older Population: 2010*

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**State Long-Term Care Report Card Released**
The AARP Public Policy Institute, in partnership with the Scan Foundation and Commonwealth Fund, released a report earlier this month that assess each state's system of long-term care services and supports. The report includes 25 measures to assess affordability and access, choice of setting/provider, quality of life/quality of care; and support for family caregivers. Support for family caregivers was measured by the percent of family caregivers who report usually or always getting assistance they need; a compilation measure that assesses state public policies that support family caregivers (i.e. paid leave, anti-discrimination policies, and spousal impoverishment); and the number of health maintenance tasks that can be delegated to direct care workers. The authors also find that the national average price for nursing home care is 241% of older people's average annual household income, which leads many Americans to exhaust their life savings and then turn to Medicaid financed long-term care. *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers Podcast Interview about the Report Kaiser Health News: "Scorecard Shows Which States Are Best At Long-Term Care Support"

**Report Analyzes Growing American Elder Population and Local Responses**
A report from the National Association of Area Agencies on Aging (n4a), analyzes how localities are responding to a growing population of elder Americans. The authors explain that by 2030 more than 70 million Americans (twice the number in 2000) will be 65 and older, comprising nearly one in five Americans. This demographic shift coincides with an economic downturn that has meant budget cuts for many of the programs serving older Americans. Despite the weak economy, many local governments report improved supports for older adults, including an increase in the availability of specialized training for public safety and emergency staff (24% in 2005 to 59% in 2010); and an increase of in-home support services (71% in 2005 to 77% in 2010). The three top challenges reported by local governments in 2010 were financial/funding shortages, transportation and housing while in 2005, they were housing, financial issues and various health issues. Urban communities (1,000,000+) were far more likely to report an availability of health care services to meet a range of needs than rural communities. Availability of subsidized housing was reduced from 70% in 2005 to 63% in 2010, and property tax relief for older adults also declined from 72% in 2005 to 54% in 2010. n4a: "The Maturing of America: Communities Moving Forward for an Aging Population"
Land Use, Transportation, and Housing Policies That Enable Aging in Place

AARP's Public Policy Institute released a report that examines how state and local policies can support aging in place. For example, a land use policy that encourages/requires implementing transit-oriented development near (half mile or less) a transit stop can help can enable seniors who are no longer driving to access transit. In 25 states and DC and Puerto Rico, "complete streets" policies are intended to allow all users (including cyclists, walkers, motorcyclists, transit riders), regardless of age or disability, to navigate easily. Naturally Occurring Retirement Communities (NORC) in six states and Communities for a Lifetime in four states are highlighted as models that allow seniors to remain in their homes instead of moving to assisted living or retirement centers.


Fifteen Million Seniors Will Have Poor Transit Access by 2015

A report analyzed the adequacy of public transportation in 241 metropolitan areas with a population of 65,000 or more in the year 2000 and found that 11.5 million Americans aged 65 and older experienced poor transit access. The authors project that if the trend to "age in place" continues (a trend preferred by 88% of adults aged 65 or older), then 15.5 million older Americans will experience poor transit access by 2015. This trend is worse in rural communities, where approximately 40% of rural residents lack access to public transportation. While older adults prefer to continue driving, more than 20% of seniors aged 65 and older do not drive at all. The author's suggestions include providing increased, dedicated funding for a variety of public transportation options. They also suggest that transit programs should continue receiving funding from the Highway Trust Fund and state and local departments of transportation as well as transit operators are encouraged to involve seniors and community stakeholders when developing transportation plans.

Transportation for America: "Fixing the Mobility Crisis Threatening the Baby Boom Generation"

Madison.com "Biz Beat: Aging Boomers Need Transit, Report Warns"

Aging Tsunami or Opportunity to Try New Strategies?

A report focused on member countries of the Organization for Economic Co-Operation and Development (the U.S. is a member) suggests that while changing demographics have the potential to strain healthcare and social service programs, this shift can also be seen as an opportunity to adapt programs and policies and try new approaches. The authors explain that the first approach views the growing elder population as a burden that will lead to higher costs and potential conflicts between generations about spending priorities. The alternative approach, which the authors advocate for, is to acknowledge the challenges of the demographic shift while also recognizing that longer life spans could mean more people who can work and volunteer in ways that will benefit the rest of society. They also advocate for a "life course" approach that focuses on prevention and a stronger focus on healthy lifestyles. The authors suggest that flexible workplace policies, gradual retirement, improved housing options, new methods of providing health care and social programs and new technologies can all contribute to longer, healthier lives while delaying the need for costly, intensive institutional care.

The International Longevity Centre - UK (ILC-UK): "Aging, Health and Innovation: Policy Reforms to Facilitate Healthy and Active Ageing in OECD Countries"

OECD Report Addresses Long-Term Care Strategies for 34 Member Countries

A report from the Organization for Economic Cooperation and Development (OECD) addresses the growing aged population in the 34 member countries (including the U.S.), the implications of this shift, and possible strategies to address it. In OECD member countries, more than one in ten adults 50 years or older provides caregiving (usually unpaid) and almost two-thirds are women. According to the authors, without adequate supports, caregiving, especially high-intensity caregiving, leads to a reduction in the labor supply, higher risks of poverty, and a 20% higher prevalence of mental health issues for caregivers as compared to non-caregivers. The authors outline current strategies in member countries, including improved work/life balance policies, paying family caregivers, providing support services like respite, and better recognition and training for direct care workers. For financing long-term care, the authors suggest that universal LTC coverage would allow for the pooling of risk, though also suggest more precise targeting of benefits to those most in need. The Telegraph analyzed the data on the United Kingdom, which is expected to have the highest long-term care expenditures by 2050 of any of the countries studied. OECD: "Help Wanted? Providing and Paying for Long-term Care"

Telegraph: "OECD: huge elderly care bill threatens family ties"
California: State Assembly Committee on Aging and Long-Term Care Hearing

A hearing on May 17, 2011 focused on the state's approach (or lack thereof) to providing a high-functioning, supportive long-term care system for Californians. Stuart Drown, Executive Director of the Little Hoover Commission, testified about the commission's recently released report that analyzed the challenges of seven different agencies overseeing 36 different programs serving elderly and disabled Californians. Drown explained that current problems include consumer confusion, a lack of leadership and authority at the state level, and poor data collection limiting the state's ability to target services to those most in need. Dr. Steven Wallace from UCLA's Center for Health Policy Research, shared the results from a focus group with 33 low-income seniors who rely on a patchwork of supportive programs to remain in their homes and who would be severely impacted by program cuts.

Karen Keesler, Executive Eirector of the California Association of Public Authorities for IHSS, shredded a safety net during her testimony to demonstrate the impact of repeated cuts to IHSS, MSSP, Medi-Cal, SSI/SSP on Californians. Michelle Evans, the Executive Director of the Del Oro Caregiver Resource Center, shared examples of caregivers working with her staff, including an 86 year-old man who is a caregiver for his 79 year-old wife with Alzheimer's. Dr. Leslie Hendrickson explained that more coordinated data collection would allow policymakers to see the level of assistance needed by individual clients and to know when clients are receiving multiple services. With this information, policymakers could better project how policy changes will affect those most in need of services. Scan Foundation: Background Paper Hoover Commission: "A Long-Term Strategy for Long-Term Care"

California: LTC Summit Proceedings

The Scan Foundation organized a summit on California's long-term services and supports in September, and proceedings from the conference are now available in a report. While the state budget crunch continues to limit options, speakers at the conference also discussed strategies to make the system more consumer and family-focused. The recent AARP PPI score-card and a survey by the Scan Foundation on long-term care were both part of the event, and the afternoon session polled summit attendees on state priorities for improving long-term care. Scan Foundation Summit Proceedings

California: Foundations Release Blueprint for Partnership with State for LTC System

Earlier this year, seven California foundations released a "Blueprint for Partnerships Between California Foundations and State Policymakers" to address ways in which the foundations can collaborate with the state to improve California's Aging and Long-Term Care system. The blueprint explains that California pioneered program development during the 1970s and 1980s with programs like Alzheimer's Day Care Resource Centers, Adult Day Health Care, and On Lok, the incubator for PACE programs that have been replicated in other states. However, budget cuts, system fragmentation, term limits, and financing challenges have weakened the state's LTC system. Citing a projected 100% increase of older adults in California over the next 20 years, the report proposes ways for the seven foundations to partner with the state, including assistance with California's Section 1115 Medicaid waiver and the transition into a managed care delivery system. The foundations offer to assist with public education and outreach to consumers around the potential need for long-term care and offer assistance in research, evaluation, technical assistance and capacity building. Improving California's Aging Services and Long-Term Care System

California: Elder Index Law Enacted As More Accurate Measure Of Cost Of Living

Governor Brown signed legislation this month (AB 138) directing the California Department of Aging to begin using the Elder Index instead of the Federal Poverty Line when making decisions about how to target resources. In addition, the department will also need to report data using the Elder Index from each service area included in the state plan on aging. A research brief from UCLA released in 2010 found that older Californians needed $21,763 (on average) in order to meet basic living expenses, more than twice the amount ($10,830) suggested by the Federal Poverty Line. The San Diego Union Tribune: "New law shows how seniors are struggling" UCLA: "Older Adults Need Twice the Federal Poverty Level to Make Ends Meet"

Connecticut: Gatekeeper Program Expanded To Five Districts

The Gatekeeper program in Connecticut teaches people who work with a large number of senior citizens how to make referrals to a program that helps older adults who may be in distress. Program staff can assist people with financial planning, in-home medical care, legal advice, or transportation with the overarching goal of allowing people to age in their own homes. The program is currently run by St. Luke's Eldercare services and will be
expanded to four agencies in five districts. The state will provide $40,000 in funding to hire a staff member at each of the four organizations, and each agency is expected to make 100 presentations and 50 assessments per year. Trainings are typically targeted to groups who come into frequent contact with seniors, including postal workers, grocery store cashiers, firefighters, and hairdressers.

Hartford Courant "Innovative 'Gatekeeper' Program For Elderly To Be Expanded In State"

Kentucky: Advocate Suggests 1% Increase In Sales Tax To Pay For Elderly Services
A recent article in the Courier Journal focused on a proposal suggested by Kentuckians for Nursing Home Reform to increase the state's six percent sales tax by one percent, which the organization suggests could generate $500 million a year to fund services for the elderly. Bernie Vonderheide, the founder of the organization, explained that he is suggesting the proposal because of concerns about potential cuts to the state Department of Aging and Independent Living. This department funds services including Meals on Wheels, housekeeping and personal care. According to the article, the department has already experienced cuts of about $6 million since 2008, causing waiting lists to swell to more than 25,000 people. Courier Journal: "Advocate for elderly urges tax hike for services"

South Carolina: Town Adapts Public Safety, Transportation, and Doctor Recruitment
In Aiken, South Carolina, almost 25% of the population is older than 65, and the town is taking steps to recruit more medical professionals while also improving its transportation and public safety infrastructure. To recruit doctors, Aiken's only hospital offers expense reimbursements and guarantees a salary during their first year while they start their practice, which has resulted in 58 doctor recruits. To address public safety issues, Aiken has a free service called Smart 911 that allows residents to have critical medical information appear to emergency personnel when a call comes in from a participant's phone. Aiken is also using GPS bracelets/anklets from Project Lifesaver International to track dementia patients, with one successful "rescue" already as a result of the devices. The town has installed oversized street signs to help older drivers and the Council on Aging operates buses for residents who no longer drive. Unfortunately, the Council on Aging's budget has been reduced about 30% compared to previous years and one result is a waiting list for Meals on Wheels that has doubled in size to 650 people despite administrative staff from Meals on Wheels also taking on routes in addition to their normal duties. Kaiser Health News: "S.C. City's Aging Population Offers A Glimpse Of The Future"

Tennessee: Governor Convenses Aging Summit
In June, Tennessee Governor Bill Haslam gathered stakeholders from across the state to focus on the systems of support that enable aging in place for older Tennesseans. Working groups at the invitation-only summit discussed accessibility to care, delivery systems, and public awareness. Missouri News Horizon: "Governor's Aging Summit Convened"

Health Care Provided in the Home Needs an Update
The Agency for Healthcare Research and Quality (AHRQ) contracted with the National Research Council to research home health care issues. The resulting book (which can be downloaded as a free PDF) provides recommendations divided into four areas, including 1) health care technologies (including medical devices and health IT); 2) caregivers and care recipients; 3) residential environments for health care; and 4) research and development needs. The authors suggest that better and clearer regulations around health care applications and systems would lead to more consistent designs, especially important as medical records are becoming electronically stored and accessed. For professional caregivers, the authors explain that home health care services are "organized primarily around regulations and payments designed for inpatient or outpatient acute care settings" and suggest certification/credentialing standards for professional caregivers as well as more informational and training materials for family caregivers. The authors suggest that home modifications are an important issues for people aging in their homes and suggest federal partnerships to assist people with modifications and changing how new homes are designed. The authors conclude that while research has been conducted on improving home health care, it has not yet been effectively translated into practice.

The National Academies Press: "Health Care Comes Home: The Human Factors" (Book/chapters can be downloaded free as PDF's)
Preventing for Shifting Demographics Outside of the U.S.

Austria: Shift from "Long-Term Care" to "Active Ageing"
A report from the European Centre for Social Welfare Policy and Research analyzes shifting from a passive approach of "long-term care" and "prevention" to a more empowering approach of "Active Ageing." The authors focus on Austria and note that long-term care is increasing being recognized as a central social and health policy field of action in Europe. Successful development of the approach will require better integration between health and social systems, more coordination between formal and informal care sectors, and the development of "harmonized and transparent quality standards, funding flows and management structures." While Austria has made considerable progress, similar to other countries, the "coordination cooperation between the social and acute medical care sector remains a problem area..." Citing data that 80 to 85% of vulnerable older adults are currently cared for at home by a family member, the author cautions that surveys show the majority of Austrians do not want to be live-in caregivers, but also suggests that "frequent decisions for permanent nursing home admission" are problematic. Recommendations include a stronger focus on supporting older caregivers who face higher health risks because of their caregiving, better coordinated networks of appropriate care, and overall better coordination among supportive systems.

European Centre: "Active Ageing and Prevention in the Context of Long-Term Care"

Australia Aged Care System Will Need to Adapt
A draft report by an Australian government commission suggests that Australia will need to make some dramatic changes in order to provide care for an aging population that will need complex care for diseases including dementia and diabetes. The authors project that the number of people aged 85 and older will increase from 400,000 in 2010 to 1.8 million by 2050. An article in the Sydney Morning Herald covering the report quoted Doctor Germaine Greer, a public health advocate, who pointed out that women are disproportionately impacted by caregiving because most of the women in residential care are women and most of the informal and professional caregivers are also women.

Australian Government Productivity Commission "Caring for Older Australians"

Sydney Morning Herald: "Productivity report on aged care welcome start to debate"

Australia: Counting the Family Home to Defray Health Care Costs
Australia recently released a draft report on overhauling its aged care system and one of the most controversial proposals would require a family home to count when calculating a person's ability to pay for care. The report was released in January and the Courier Mail recently analyzed some of those findings. In 40 years 3.6 million Australians will need elder care, up four times from the current year. Another proposal would require wealthy people to pay 25% of the cost of their care. Before a final report is submitted, the report details will undergo public hearings. The Commission's 42 recommendations provide for more streamlined support services choices, but the crucial question is how to fund it. Courier Mail: "Family home at crux of aged-care debate"

Australia: Report Provides Statistical Overview on Residential Aged Care Facilities
The Australian Government released a report this month with demographics of residents in aged care facilities for 2009 that found the government spent an additional $1 billion on aged care as compared to the year before. Seventy percent of the 164,000 residents are female, and over 52% of residents (83,500) have a recorded diagnosis of dementia. AIHW: "Residential aged care in Australia 2009-10: A statistical overview"

Australia: Gvt. Report Calls for Dramatic Shifts in Long-Term Care Infrastructure
The Australia government released a report on August 8 that provides an overview of the country's current long-term care needs, an analysis of the challenges currently facing the currently, and proposals to improve. Challenges cited by the authors include difficult navigation, variable quality, limited services, workforce shortages, and inconsistent and inequitable co-contributions. The suggested improvements to the system would result in a National Disability Insurance System (NDIS) that would benefit about 410,000 people who are currently living with a significant disability. NDIS would cover care and support services including therapy, domestic help with cooking, cleaning and shopping, home and vehicle modifications and assistance with activities of daily living. The changes would also come with a price tag of an additional $6.5 billion a year beyond the $7 billion that is already spent annually. Australian Government Productivity Commission: "Caring for Older Australians"
Canada: "Caregiver Recognition Act" Introduced
Legislation was introduced in May in Manitoba to better recognize and support family caregivers. The Caregiver Recognition Act would institute a progress report every two years to evaluate caregiver needs and supports; create a caregiver website with centralized information on support groups, financial benefits, and human-resource policies; and also create a Caregiver Advisory Committee to provide information and advice to the Healthy Living, Youth, and Seniors Minister. The Act would also proclaim the first Tuesday in April as Caregiver Recognition Day, and would create general principles relating to caregivers and their treatment by the public, health professionals, and their employers. In making the announcement, the Minister noted that a 2007 survey found that about one in five Manitobans aged 45 and over reported serving as a caregiver to an older adult. The Manitoba government also recently included a 25% increase in the maximum annual Primary Caregiver Tax Credit, now worth $1,275 per care recipient. The legislation is part of the "Age-Friendly Manitoba Initiative," started in 2008 to allow older Manitobans to age in place.

Manitoba Government "Caregiver Recognition Act"

Canadian Elder Standard Measures Cost of Living and Long-Term Home Care
A research paper from the Social and Economic Dimensions of an Aging Population program at McMaster University (SEDAP) provides the after-tax income needed for Canadian elders living in five cities, known as the Canadian Elder Standard (CES). The authors examine the typical expenses for food, shelter, medical, transportation, miscellaneous living items, and home-based long-term care for elders. The Canadian standard is similar to a U.S. measure, the Elder Economic Security Index. The CES for the five cities ranges from $11,346 (single) $15,454 (couple) in Montreal to $17,213 (single) $21,636 (couple) in Toronto (all figures are in Canadian dollars). The authors explain: "From among a Canadian elder's basic expenses (shelter, food, transportation, medical care, miscellaneous and home-based long-term care), the costs associated with home-based long-term care threatens to be the most severe. This expense is also, unfortunately, the least predictable and the most likely to affect poor elders."

SEDAP: "The Canadian Elder Standard Pricing the Cost of Basic Needs for the Canadian Elderly"

"If it takes the threat of a lawsuit to get your delinquent kids to visit, what exactly do you hope to chat about over tea?"

Canada: Researcher Says Gray Tsunami is Actually Gray Glacier
Two studies in the most recent issue of Healthcare Policy suggest that concerns about a medical system unable to handle a "silver tsunami" may be unfounded. The first study examines total health care spending in British Columbia from 1996 to 2006 and finds that the aging of the population contributed less than 1% per year to spending on medical, hospital, and pharmaceutical care. While per capita expenditures on acute hospital care and doctor visits increased slightly faster than the 17% rate of inflation, per capita spending on prescription drugs rose by 140%. The authors forecast healthcare spending to 2036 and suggest that the aging of the population will continue to exert only modest influence on overall healthcare costs. The second study examined a perceived shortage of doctors in Canada, and finds that physician payments increased by one percent ($174 million) between 1996/97 and 2005/06 (even after adjusting for inflation, population growth and population aging). They suggest that the perceived shortage may be driven by a 64% increase in spending on diagnostic services for people aged 75 and older, which may be taking the place of "hands-on" care.

EurakAlert: "Fear of 'gray tsunami' overblown: UBC research"

Healthcare Policy: Population Aging and the Determinants of Healthcare Expenditures: The Case of Hospital, Medical and Pharmaceutical Care in British Columbia, 1996 to 2006 (Article is Free)

Healthcare Policy: Diagnosing Senescence: Contributions to Physician Expenditure Increases in British Columbia, 1996/97 to 2005/06 (Abstract is Free)

Chinese Consider Requiring Children to Visit
A recent commentary in the Globe and Mail examined a legislative proposal being considered in China to require children to visit their parents or face fines or jail time. The author explains that China's "one-child policy" may have reduced the number of potential caregivers to care for an aging population. In addition, economic changes have forced children to move away from their parents, and the author cites the example of a 35-year old mother who would like to visit her parents, but is troubled by the cost of a train ticket that would consume one-third of her monthly budget. The author concludes: "Legislating relationships is a tricky business. If it takes the threat of a lawsuit to get your delinquent kids to visit, what exactly do you hope to chat about over tea?"

Globe and Mail: "China trying to force children to visit aging parents"
India: Country is Ill-Equipped to Provide Care for 81 Million Elderly
A recent series focusing on India (The Shiva Rules) by the Global Post addressed India's growing elderly population and how cultural and economic changes may leave many elders to fend for themselves. Historically, India's culture of respect for the elderly translated to multi-generational living with parents cared for by their sons and daughters-in-law in the same home. However, with economic changes, children move to cities or to the U.S. or Europe, and fewer than 40% of Indians now live in joint families, leaving some parents to feel neglected or abandoned by their families, especially since an estimated 50% of elderly are financially dependent on others. Nursing homes are also considered taboo because they go against the idea of caring for one's family. While Indians who worked in the formal sector receive pensions, more than 90% of the population work outside the formal sector. A pension program for the very poor provides 200 rupees ($4.50) a month, and legislation recently enacted lowered the eligibility age to 60 and will give 500 rupees ($11.30) a month to those over the age of 80. Health care for the elderly is cited as an issue because of lack of specialized geriatric services and lack of access to care. Global Post: Shiva Rules: "Will the elderly bring down India?"

Ireland: Waiting Lists for Nursing Home Care
The Independent reports that about 1,100 mostly elderly people who have already been assessed as needing nursing home care are still on waiting lists and many are currently occupying beds in acute hospitals. The people have been approved for the government's Fair Deal scheme, but the program's budget has not been sufficient to meet demand. Independent: "1,100 elderly on waiting list for nursing home"

Ontario Report: 4,500 Patients Currently in Hospital Beds Should Be Elsewhere
A report commissioned by the Ontario Health Ministry and released earlier this summer suggests that Ontario's infrastructure for long-term care is in need of improvement, especially in regards to assessing patients and connecting them to appropriate levels of care. The author suggests that the current system relies heavily on acute care hospital resources and a culture that focuses on permanent placement of seniors instead of remaining at home with supportive services. This culture often leads to patients being admitted to the ER, then acute care hospital admission, and then waiting in a hospital bed while waiting for alternate levels of care. Recommendations are grouped into six "pillars," including: primary care, community care continuum, special needs populations, acute care hospitals, assess and restore, and LTC community.

Report: Caring for Our Aging Population and Addressing Alternate Level of Care (ALC)
Taiwan: Cabinet Approves Bill Creating Long-Term Care Reserve Fund
The Taiwan government approved a draft law requiring the government to provide almost $34 million for a reserve fund to pay for long-term care. Premier Wu Den-yih explained that the law is the first step to creating long-term care insurance in the future. Under the bill, long-term care is defined as medical or personal assistance for a person who is expected to have a physical or mental disability for longer than six months. Caregivers must be licensed and will be required to take refresher courses. China Post: "Cabinet approves long-term elderly care bill"

United Kingdom: Policy Responses to Dementia Should Address "Feminization of Aging"
The International Longevity Centre published a report in August 2011 that suggests policymakers begin to address the disproportionate dementia burden that women bear. The authors explain that women are more vulnerable to prolonged inequality because of lower levels of education and a greater risk of poverty. Because caregivers are more likely to be women, they are also exposed to increased health and financial risks associated with caregiving. The authors recommend incorporating a gender dimension to health policy and programs; including gender as a key health determinant in prevention of dementia; disaggregating dementia research by gender and age; equal representation by men and women for policy decision-making roles; and more interdisciplinary research that incorporates the biological and social models of health for men and women. International Longevity Centre: "Women and Dementia - Not forgotten"

United Kingdom Lowers Asset Test Threshold for Residential Care
An article in the Telegraph analyzed a recent government decision to not index the asset test for people living in residential care homes, a move that effectively raises the amount that people will have to pay as part of their care. Similar to the Medicaid program in the U.S., there is an asset test in the United Kingdom for people seeking residential long-term care. If a person has savings and assets (including a house) of more than 23,250 pounds (about $38,000), then they have to pay the full cost of care of 500 pounds a week (about $815) until their assets are below the asset test. While the asset test was historically increased every year to account for inflation, the government decided to freeze the asset test, which the author suggests amounts to an effective ten percent cut in the threshold. Governments around the
world are struggling to plan for providing and paying for care for the rapidly increasing elderly population, and a recent plan in Australia also suggested including a family home when calculating a person's ability to pay for long-term care. *Telegraph* "Thousands more will have to sell homes for elderly care"

See also:


Older Age Working Group: “Age of Opportunity: Transforming the lives of older people in poverty: A policy report” (June 2011)

*The Age*: “Aged-care-sector leader warns of looming challenges”

*The Guardian*: “Social care is on the critical list. But Dilnot won’t cure it”

*The Globe and Mail*: “Chronically ill baby boomers clogging doctors’ offices: study” (June 2001)

Direct Care Workers

In addition to family caregivers, direct care workers are an integral part of the country’s long-term care system. The most important development of 2011 has been a possible revision to the “companionship exemption” in the Fair Labor Standards Act that currently limits minimum wage and overtime protections for direct care workers. The Department of Labor published a Notice of Proposed Rulemaking related to the exemption on December 27, 2011.

**Companionship Exemption May Be Removed**

The Obama Administration announced in December, 2011, that the Department of Labor intends to update the companionship exemption in the Fair Labor Standards Act that currently exempts direct care workers from receiving overtime or minimum wage protections. According to the *New York Times*, Labor Secretary Solis said that Medicare or Medicaid, which pay pays for 75% of the nation's home care costs, would pay between $31 million and $169 million more each year as a result of the change, representing .06% to .29% of federal spending on home care. The Labor Department also suggested that the proposal would "level the playing field" for home health care agencies who would no longer feel pressure to underpay their workers in order to gain a competitive edge. *New York Times*: "Wage Protection for Home Care Workers"

PHI released a report in December with in-depth analysis on the estimated 2.5 million direct care workers in the U.S. who provide care for the elderly and disabled. PHI: "Caring in America: A Guide to America's Home Care Workforce"

**Nursing Home Industry Lobbies against Providing Health Care Coverage for Employees**

The *New York Times* reported in May 2011 on a lobbying campaign by nursing home and home care agencies to be exempted from providing health care insurance for their workers. Under the Affordable Care Act, companies with more than 50 employees will be required to provide health care for their employees or pay fines. Representatives from nursing homes cite low reimbursement rates from Medicare and Medicaid as limiting their ability to pay for health care coverage for their workers. *New York Times*: "Nursing Homes Seek Exemptions From Health Law"

**Roadmap for Improving Direct Care Jobs and Quality of Care**

A report from PHI outlines challenges and opportunities to improving the quality of direct care provided to care recipients while also improving the quality of direct care jobs. Citing the 4.5 million elders and people with disabilities who currently receive care in the U.S., the 3.2 million direct-care workers who provide these services, and the expected growth in need for this workforce, the author outlines a number of challenges and strategies. One of the key issues is compensation for direct care workers- the median hourly wage in 2009 was $10.58 as compared to the median for all U.S. workers of $15.95. In addition to low wages, direct care workers also face a lack of hours (48% in 2009 worked less than full-time year-round), and lack access to health care, with an estimated 900,000 direct-care workers in 2009 lacking health care coverage. The author outlines nine elements of quality jobs as well as essential elements of quality care for consumers, including self-direction, keeping dignity and privacy, and individualized care. PHI: "Improving Jobs and Care: A National Sector Strategy"
Direct Care Workers United for Change Launch Credential Program
A new competency-based test for direct care workers was launched to improve the quality of long term care for the elderly and for those who depend on personal care assistance, to maintain their quality of life, dignity and independence. The credential for personal assistance workers offers to professionalize the industry by providing the following: 1) providing elders, people with disabilities and their families with a reliable way to assess the competency of those they hire; 2) giving agency employers a customer-centered assessment tool; 3) establishing a national standard for state policy makers; and 4) allowing workers in this field to demonstrate their professionalism and skill. Direct Care Alliance: "DCA Launches Personal Care and Support Credential"

International Treaty Focuses on Protections for Domestic Workers
Human Rights Watch (HRW) announced in June 2011 that a new international treaty focused on extending domestic rights to all domestic workers, including caregivers, nannies, and housekeepers has been approved by International Labor Organization (ILO) members. HRW lobbied the ILO, which began considering international standards on domestic workers three years ago, and the ILO agreed to create a legally binding convention. During the voting on the treaty, 396 delegates voted for the convention that would extend basic labor rights to all domestic workers, requires governments to set a minimum age for domestic work, and would provide girls with access to education. HRW said it will press governments to ratify the treaty and bring their national laws in line with it. HRW "A Victory for Domestic Workers"

National Median Hourly Wage for Personal Care Aides Declined in 2010
PHI PolicyWorks released its State Chart Book on Wages for Personal Care Aides and the authors find that the national median hourly wage for Personal Care Aides (PCA's) declined from $9.46 in 2009 to $9.44 in 2010, driven by a drop in wages in 17 states. During the ten year period from 2000 to 2010, 23 states and the District of Columbia showed increases in real median wages, however, only four states showed annual increases of at least two percent. Thirty-four states reported average hourly wages that fell below 200% of the Federal Poverty Level ($10.42 an hour) in 2010, thus potentially qualifying workers for state and federal benefit programs. A federal bill has been introduced, the Direct Care Job Quality Improvement Act, that would eliminate the companionship exemption in the Fair Labor Standards Act that currently exempts home care workers from receiving a guaranteed minimum wage and overtime. The report by PHI includes state-by-state data. PHI: "State Chart Book on Wages for Personal Care Aides, 2000-2010" FCA Legislation Center: "Direct Care Job Quality Improvement Act"

Changes to Social Security Would Be Harmful for Direct Care Workers
A report by the Direct Care Alliance and the Center for Economic and Policy Research analyzes the potential impact on direct care workers if changes are made to Social Security. The author explains that Social Security is especially important to direct care workers because only about one in four participate in an employer-provided retirement program and the government has also destroyed an important source of wealth for many Americans. The report analyzes proposals to increase the retirement age to 67 and to reduce the Cost of Living Adjustment, both of which would be harmful for direct care workers. The author includes several policy proposals developed by the Commission to Modernize Social Security, including eliminating the income cap on Social Security (currently, earnings above $106,800 are not taxed); increasing the special minimum benefit to 125% of the poverty threshold; implementing caregiver credits; and increasing the survivor's benefit for widowed spouses. DCA/CEPR: "Maintaining and Improving Social Security for Direct Care Worker"

Subsidizing Caregiver Wages Could Reduce Turnover by one-third
An article in the Journal of Disability Policy Studies examines turnover of professional caregivers and finds that because training costs are paid for by the government, providers may have less incentive to reduce turnover. While the study uses data on long-term community-based residential services for persons with developmental disabilities, they suggest that their results also carry over to nursing homes and elder care centers. In Illinois, they suggest that the state’s "blind-matching system, based on geography and if a provider has an empty bed" means that consumers aren't able to "discipline" providers for lower-quality care that happens due to high turnover. Citing related research conducted with the same data, the authors suggest that increasing compensation by 24 to 31% (at an annual cost of $4,824 to $6,143) would decrease turnover by 1/3. By subsidizing wages or providing other incentives to providers, the government could reduce turnover, thus improving quality.
Journal of Disability Policy Studies: "Should Government Subsidize Caregiver Wages? Some Evidence on Worker Turnover and the Cost of Long-
Invest in Home-Based Health Care and Early Childhood Education

A recent working paper from the Levy Economics Institute at Bard College suggests that spending an additional $50 billion on social care provision—both early childhood education and home health care—would provide strong dividends for both the care recipients and the newly employed care providers. The authors explain that there is a current unmet need for early childhood education, and research has found strong returns on investing in early childhood education. Similarly, while family caregivers provide the majority of long-term care, this also comes with costs, including absenteeism and/or total exit from the labor market. By injecting $25 billion into existing programs (not creating new government programs), the authors' model finds that 1.2 million jobs would be created, with 45% of jobs going to workers from households with income below $39,000 a year. Levy Economics Institute: "Unpaid and Paid Care: The Effects of Child Care and Elder Care on the Standard of Living"

PHI: State Profiles of Direct-Care Workforce

PHI announced the release of a new tool that provides a comprehensive data profile on each state's direct care workforce, including nursing home aides, home health aides, and personal care assistants. The tool includes data on workforce size and projected employment growth, trends in wages, and information on health insurance coverage rates and reliance on public assistance. In addition, the tool provides links to legislation/regulatory developments, state initiatives, and employer best practices. PHI: State Data Center

Iowa: Direct Care Professionals Turnover Will Cost $126 Million in 2011

A report by the Iowa Direct Care Workforce Initiative estimates that each turnover of a direct care worker in Iowa costs $3,749 in direct expenses for the employer. Costs include staff time and expenses associated with covering the work during the vacancy, recruiting, hiring, screening, testing, and background checks, and training/orientation costs for new hires. The authors explain that there are also indirect costs that are more difficult to quantify, including lower productivity by departing and remaining workers, reduced quality of services because of lack of continuity, increased errors, lost clients and damaged community image, and decreased employee morale. If indirect costs are included, each turnover costs a total of $6,793. The authors suggest in addition to higher wages and better benefits, the development of a knowledgeable and well-trained workforce will allow workers to succeed in this field and reduce turnover. The authors also expect that Iowa's new credentialing system for direct care workers will reduce turnover. Iowa Direct Care Workforce Initiative

Iowa: State Senator Participates in "Come Care with Me Days"

Iowa State Senator Jeff Danielson participated in a PHI "Come Care With Me" day where he trailed Kelly Stokes, who is a CNA at a long-term care facility in Waterloo, IA. Despite being a firefighter, Senator Danielson expressed surprise at the physical toll of the direct care work. He explained that he thinks the public may underestimate the importance of direct care workers, and suggested that direct care workers need to be paid well and receive health care benefits. PHI: "Iowa State Senator Participates in "Come Care with Me" Day"

Massachusetts: Legislation Focuses on State's Direct-Care Workforce

PHI National reported on a hearing in November 2011, focused on legislation (S.45) to assess the adequacy of the state's long-term care workforce. The legislation would create a task force to gather and analyze data on the number of direct-care workers, turnover, and wages and benefits. The members would also be expected to assess the state's current training/credentialing infrastructure and develop policies to ensure there are sufficient number of employees for home and community-based settings. A report would be due by December 31, 2012. PHI National: "Hearing Held on Bill to Establish a Massachusetts Direct-Care Workforce Task Force"

Washington State: Voters Approve Increasing Training for Long-Term Care Workers

Initiative 1163 was approved by Washington state voters and according to the Seattle Times, the law will more than double the required training for direct care workers from 34 to 75 hours. The law also requires certification and more rigorous background checks for workers. A similar initiative was approved in 2008 but implementation was delayed because of state budget pressures, a move that was supported by SEIU (which helped put the ballot on the measure in both years), however, SEIU has said it will not support a delay in 2011. The measure is expected to require $32 million in new state spending, part of which will be offset by federal matching money. Washington State also passed
paid family leave in 2007, but postponed implementation of the law until October 2015, citing budget pressures. *Seattle Times: "Long-term-care training approved"

**Washington State: Judge: DHSS Owes Caregivers $96 Million**

The *Seattle Times* reported that a county judge in Washington State ruled that Washington's Department of Social and Health Services (DSHS) owes 22,000 home-care workers about $96 million in back pay and accrued interest. The lawsuit is based on a 2003 decision by Washington State to pay caregivers 15% less if they lived in the same household as the care recipient (in the state’s Medicaid program). While the state plans to appeal the ruling, an attorney for the plaintiffs suggests that interest could cost $30,000 a day if the plaintiffs ultimately prevail. The state reversed the policy after the state Supreme Court ruled against the state in 2007, however, it never reimbursed caregivers for the four years of "lost" payments. *Seattle Times: "Judge: DSHS owes $96 million to caregivers"

See also:

- California Senate Office of Oversight and Outcomes: “Caregiver Roulette: California Fails to Screen those who Care for the Elderly at Home” (April 2011)
- *Napa Valley Register*: “Caregiver Law in Napa is First in California” (June 2011)
- PHI: Kansas Caregiver to Receive Wage Increase from State (June 2011)
- *Sydney Morning Herald*: “Courses in aged care ‘need audit’” (August 2011)
- *TheDay.com* “Critics attack Malloy for opening door to unionization” (September 2011)

**Institutional Long-term Care**

This section includes developments both in nursing home care and assisted living. Quality of care, staffing levels, and overall regulation of assisted living (or lack thereof) was a large focus of research and legislation in 2011.

**Nursing Home Survey on Patient Safety Culture**

AHRQ released results from a survey of 226 nursing homes and 16,515 nursing home staff that measures the culture of resident safety in nursing homes from a staff perspective. The survey measures 12 areas of patient safety culture. Of the participating nursing homes, 48% are for profit. The areas of strength include the overall perception of resident safety (average 86% positive response), and feedback and communication about incidents (average 84% positive response). Areas for improvement include non-punitive responses to mistakes (average 51% positive response), and sufficient staffing to handle the workload, meet resident's needs, and keep residents safe (52% positive response).

The report compares responses to questions about patient safety, whether or not an employee would tell a friend it is a safe nursing home, and overall safety ratings. Non-profit/government nursing homes and smaller nursing homes (49 or fewer beds) had the highest ratings for patient safety culture, highest rating of respondents who would tell friends this is a safe nursing home, and the highest percentage of respondents who gave their nursing homes an overall rating of "excellent" or "very good."

Administrators/Managers and Physicians gave the highest positive responses across patient safety culture composites (79% positive) while Nursing Assistants/Aides gave the lowest (63% positive), with similar gaps between whether or not a person would make a referral for friends and overall ratings on resident safety of "Excellent" or "Very Good." There were also differences in respondent's views on patient safety based on whether or not the respondent had direct interaction with residents; those with direct interaction were more negative than those who do not interact directly with residents. Respondents who worked day shifts also gave higher ratings as compared to those who worked night shifts. AHRQ: "Nursing Home Survey on Patient Safety Culture: 2011 User Comparative Database Report"

**Hearing on Regulation of Assisted Living Facilities**

The United States Senate Special Committee on Aging held a hearing focused on regulation of assisted living facilities in November, 2011. One of the witnesses was a daughter whose mother's death at an assisted living facility in Florida prompted an investigation into regulation (or lack thereof) into assisted living facilities in Florida. Other representatives discussed current regulation of assisted living facilities at the state levels. The testimony from Leading Age cited the fact that 37 states have some form of disclosure statement that is provided to prospective residents and 49 states have
regulatory requirements for residency agreements that mandates that they include certain consumer protections. Another effort cited was the Assisted Living Disclosure Collaborative, which will ultimately result in a uniform disclosure tool that will inform consumers about the services provided at an individual assisted living provider. 

US Senate Special Committee on Aging Hearing: "Ensuring Quality and Oversight in Assisted Living"

2010 National Survey of Residential Care Facilities
The National Center for Health Statistics at the Center for Disease Control released results from its 2010 survey of the 31,000 residential care facilities (RCF) in the U.S. that provide 971,000 beds nationwide. About half of RCFs were small facilities with 4-10 beds, and about 4 in 10 RCFs had one or more residents who had some or all of their long-term care services paid by Medicaid, while extra large RCFs (100+ beds) were least likely (32%) to serve residents whose services were paid for by Medicaid. Forty-two percent of RCFs are located in the West, while only 8% are located in the Northeast. NCHS: "Residential Care Facilities: A Key Sector in the Spectrum of Long-term Care Providers in the United States"

Certified Nursing Assistant Turnover in Nursing Homes
A study in the October 2011 issue of the Gerontologist focuses on Certified Nursing Assistant (CNA) turnover using a random sample of CNAs working at least 30 hours a week in Pennsylvania. The CNAs completed a phone survey at the beginning of the survey and completed a follow-up survey one year later. Of the 620 who responded to both surveys, 85.8% remained in their position, 8.4% switched to another facility, and 5.8% left the industry. The authors explain CNAs who left the industry had lower job satisfaction and emotional well-being and also left for health reasons. The authors suggest that nursing home administrators can use this data to understand why staff leave their jobs. The Gerontologist: “Stayers, Leavers, and Switchers Among Certified Nursing Assistants in Nursing Homes: A Longitudinal Investigation of Turnover Intent, Staff Retention, and Turnover”

Higher Number of Deficiencies in Private Investment and For-Profit Nursing Homes
A GAO report analyzes nursing homes that were acquired by private investment (PI) firms and whether or not this ownership affects deficiency rates on state surveys, nurse staffing levels, and financial performance. The authors find that on average, PI and other for-profit homes had more total deficiencies than nonprofit homes before (2003) and after (2009) acquisition. While the reported total nurse staffing ratios (hours per resident per day) were lower in PI homes, there were higher numbers of registered nurses in PI homes than in other homes. GAO: "Nursing Homes: Private Investment Homes Sometimes Differed from Others in Deficiencies, Staffing, and Financial Performance"

Black Resident's Higher Rate of Bed Sores May Correlate to Low Staffing Levels
A study in the July 2011 issue of the Journal of the American Medical Association examines data on the rate of pressure ulcers (bed sores) for 2.1 million white and 346,808 black residents of 12,473 nursing homes from 2003 to 2008. While there was an overall reduction in bed sores during this period, a large racial disparity was still present and the authors conclude that it is due in part to where residents receive care. The pressure ulcer rate for black residents in 2003 was 16.8% and the rate for white residents was 11.4%. In 2008, the rate for black residents decreased to 14.6% and 9.6% for white residents. In nursing homes with the highest percentage of black residents, residents of both races were at least 30% more likely to develop bed sores than residents in nursing homes with few or no black residents. Dr. Yue Li, one of the authors, noted that nursing homes with higher concentrations of black residents generally have lower staffing levels of registered nurses and nursing assistants, and tend to be larger for-profit and urban facilities. Journal of the American Medical Association: "Association of Race and Sites of Care With Pressure Ulcers in High-Risk Nursing Home Residents" (abstract is free)

Suggestions for Choosing Nursing Homes
In an interview with the "You Should Know" program, Janet Wells, the director of public policy for Consumer Voice, provided suggestions for family members in researching nursing homes. Prior to choosing a nursing home, Wells suggests visiting several nursing homes, and observing the treatment of residents- for example, are they in restraints, what are the interactions like between staff and residents, and do residents receive adequate attention? Wells recommends trying the food at the facility and reviewing the inspection reports that nursing homes are required to provide. Another place to check is the state long-term care ombudsman office to see the number and nature of complaints and the state-level licensing agency. In about half of the states, there are coalitions formed by consumers and their family members who can assist with learning about nursing home options. Wells explained that Consumer Voice has advocated for mandatory minimum staffing levels at nursing homes but has not yet succeeded. If family members have complaints, she suggested the state long-term care ombudsman as a first step, and explained that
regulating assisted living is highly critical of the FL Agency for Health Care A Florida: Regulation of Assisted Living Facilities features visits to long centered approach to long setting and the importance of using a person and family independence, dignity, and activities, regardless of their they discuss the importance of people retaining their the C Ma Pro the National Association of Professional Geriatric Care professionals, and will charge an average of $300 to care management agency that employs licensed better option ma to the most expensive option. could motivate placement specialists to steer customers "referral bonus" of $3,000 for a high more of the first month's rent payment which can amount to 50% or more of the first month's rent payment- amounting to a "referral bonus" of $3,000 for a high-end facility. This could motivate placement specialists to steer customers to the most expensive option. Spiegel suggests that a better option may be to hire a brick-and-mortar geriatric care management agency that employs licensed professionals, and will charge an average of $300 to $800 for an assessment. He suggests using a listing on the National Association of Professional Geriatric Care Managers Web Site to find these agencies. Kaiser Health News: "The Questionable Lure Of Free Long-Term Care Placement Services"

Long-Term Care Options Lynn Friss Feinberg from the AARP Public Policy Institute and Larry Minnix, from LeadingAge, participated in an episode of Talking Health to discuss long-term care options with Mike Gilliam. The episode aired on CUNY-TV in October and is also available on the Commonwealth Fund Website. During the show, they discuss the importance of people retaining their independence, dignity, and activities, regardless of their setting and the importance of using a person and family-centered approach to long-term care. The episode also features visits to long-term care facilities and interviews with residents. CUNY-TV "Talking Health"

Florida: Regulation of Assisted Living Facilities A legislative study conducted by the Florida state Senate is highly critical of the FL Agency for Health Care Administration (AHCA) and its current approach to regulating assisted living facilities (ALF's). The authors suggest stripping AHCA's discretion about the amount of fines imposed on ALF's when serious abuses like intentional death or negligence occur or if deficiencies are recurring. The authors also recommend that the state consider implementing more stringent training/qualifications for administrators and front-line staff of ALF's. Florida could also designate one state agency as the "lead agency" for regulation of ALF's, and establish a work-group of current regulators to streamline inspections. The senate staff recommends the creation of a consumer website, similar to Nursing Home Compare, that would allow consumers to compare quality of ALF's. Florida Senate, Committee on Health Regulation Report on Assisted Living Oversight

Iowa: Legislation Would Allow Nursing Home Officials to Review LTC Ombudsman Legislation introduced in Iowa would have allowed nursing home officials to review the job performance of the state's long-term care ombudsman. The version of the bill that passed in the Iowa Senate would create a committee of care providers, industry officials and regulators to review and comment on the ombudsman's investigative procedures as part of the ombudsman's annual review. The Des Moines Register reports that the bill was authored by Jeanne Yordi, Iowa's current long-term care ombudsman, who explained that the bill would bring Iowa into compliance with federal law. However, the Register suggests that this bill appears to contradict federal law that calls for each state to have a long-term care ombudsman who is independent of the industry he or she is regulating. The chairwoman of the National Association of Local Long-Term Care Ombudsmen suggested that such a committee would "represent an inherent conflict of interest." Yordi suggested that she saw the committee as a tool to bring people together to discuss industry trends and share information with her. An amendment being considered in the Iowa House would remove the language creating the committee and instead instructs the ombudsman to consider the views of the nursing home industry. Des Moines Register: "Critics: Bill touted by ombudsman for elderly creates conflict of interest"
Montana: Assisting Living Home No Longer Plans to Evict Resident Due to Rate Cuts
An assisted living center in Billings, Montana announced plans to evict one of its residents, a Korean War veteran, because of 10% cuts made in Montana's Medicaid reimbursement rate for assisted living facilities. The owner explained that she was already subsidizing the cost of Medicaid residents by about $1,000 a month and couldn't afford to receive the 10% reduced rate of $65 a day. However, Governor Schweitzer announced that the rates will only be cut by two percent instead of the ten percent cut announced at the end of the legislative session. He explained the change by saying that he didn't realize that other Medicaid providers (home care agencies, hospitals, and mental health centers) were only facing a two percent cut while assisted living facilities were facing a ten percent cut. The owner of the assisted living facility in Billings explained that while she no longer plans to evict the resident, she will no longer accept residents who are dependent on Medicaid paying their bill. There are currently 800 elderly and disabled residents in Montana who rely on a Medicaid waiver to pay for their assisted living.

Ohio: Advisory Council Recommends 20 Measures of Care Quality for Nursing Homes
The Columbus Dispatch reports that a state advisory council is recommending 20 measures to assess the quality of care provided to residents in nursing homes. Measures include whether or not residents can choose when to go to sleep and wake up, staff turnover, bedsores, urinary tract infections, and family satisfaction. State legislators are expected to vote on the measures, if approved, they will be part of a new Medicaid incentive program that will reward nursing homes with higher rates if they meet a quarter or more of the performance measures.

Pennsylvania: Providers and Consumers Slow to Embrace New Category of LTC
The Pittsburgh Post-Gazette reports that Pennsylvania launched a new category of long-term care this year known as assisted living which is designed to be a "middle ground" between nursing homes and personal care homes. While original projections by former Governor Rendell's administration suggested there would be 150 assisted living centers, there are currently only 10 (with 26 in the pipeline) and providers, including the 1,300 personal care homes, cite the cost of upgrades to residences, more training, higher licensing fees, and more regulation without increased reimbursement as a large obstacle to growth of these residential facilities. Governor Rendell's administration reversed course on seeking federal funding to help cover the cost of care for low-to-moderate income residents, which was also cited as a potential obstacle. One of the new assisted living centers profiled in the article currently charges $4,790 a month and has half of its beds occupied.

North Carolina: 43% of Nursing Home Contracts Contain Arbitration Agreements
A study by a law professor used a telephone survey and examination of admission contracts used by nursing homes in North Carolina from 2007 to 2009 and finds that 43% of the homes incorporated pre-dispute binding arbitration provisions in their admission contracts. The author explains that all of the major nursing home chains used the agreements in at least some parts of their admissions contracts while smaller companies used them more sporadically. In half of the agreements, the nursing home chooses the arbitration company, and the most popular company (36.59%) was the National Arbitration Forum, a company that agreed to stop doing business in credit card and healthcare arbitration after being sued by the Minnesota Attorney General in 2009. Almost 70% of agreements allowed for consumer rescission within 30 days, though only 40% explained that the arbitration agreement essentially waived a right to a trial by jury. In some cases, nursing homes required residents to sign the arbitration as a condition of admission, contradicting language in the agreements stating that signing the agreement was voluntary.

Texas: San Antonio City Council Considers Licensing Assisted Living Facilities
The San Antonio Express News reports that the San Antonio City Council will consider legislation to regulate an estimated 250 unlicensed assisted living facilities located in the city. The local ombudsman for the Bexar Area Agency on Aging explains that an ordinance would guide the city in efforts to license, regulate, and fine facilities that offer nonmedical care for seniors, the disabled, and people with mental illnesses.
The city council is scheduled to vote on the ordinance in January after a public awareness campaign. *San Antonio Express News: "City seeking to toughen rules for elder-care homes"*

**Wisconsin: Proposed Legislation Eases Some Regulation on Nursing Homes**

A bill was proposed in Wisconsin that would make a number of changes to how nursing homes are regulated, with the ultimate result of nursing homes paying an estimated $1.5 million less a year in forfeitures. Under current law, the state Department of Health Services enforces both state and federal rules for nursing homes, and can issue duplicate penalties under federal and state laws. This law would force the department to issue penalties under either federal or state laws— but not both. Other provisions include a 120 day limit for the department to assess forfeitures (currently there isn’t a limit), more time to pay fines (60 days instead of 10 days), more time to appeal violations (60 days instead of 10 days), more power for the state department to sue for federal rule violations (currently they can only sue under state rule violations), and more reasons for the state to revoke nursing home licenses. A law enacted in January of this year was viewed by consumer advocates as favorable to nursing homes in Wisconsin because it restricted the ability to sue for violations when a resident is hurt or killed. *Milwaukee Journal Sentinel: "Bill could save nursing homes millions in fines"

See also:

*Annals of Long-Term Care: Clinical Care and Aging: “Moving a Noncompliant Patient to Long-Term Care Against Her Wishes” (April 2011)*

*Bloomberg: “Carlyle Nursing Unit to Appeal $91.5 Million Medical Negligence Verdict” (August 2011)*

*Center for Medicare Advocacy: “Nursing Facilities’ Self-Regulation Cannot Replace Independent Surveys: A Study of Special Focus Facilities, Their Health Surveys, and Their Self-Reported Staffing and Quality Measures” (May 2011)*

*Chicago Tribune: “Making Alzheimer’s patients comfortable: Nursing home tries easing rules to improve lives of those with dementia” (January 2011)*

*GAO: “More Reliable Data and Consistent Guidance Would Improve CMS Oversight of State Complaint Investigations” (April 2011)*

*GAO: “Implementation of the Quality Indicator Survey” (April 2011)*

**Long Term Care Community Coalition: “Care and Oversight of Assisted Living in New York State” (May 2011)**

**Medical Care: “Does State Regulation of Quality Impose Costs on Nursing Homes?” (June 2011)**

**NPR: “Dozens of Questionable Deaths Seen In Assisted Care” (May 2011)**

**Pressdemocrat.com “Retirement home for gays and lesbians debuts in Fountaingrove” (June 2011)**


**The New Old Age: For Elderly Muslims, Few Care Options Outside the Home (March 2011)**

The National Consumer Voice for Quality Long-Term Care: “The High Cost of Poor Care: The Financial Case for Prevention in America’s Nursing Homes” (April 2011)

**Seniors Housing & Care Journal: “Lessons Learned from the Green House Model” (2011)**

**Trib.Com: “Wyoming's first Green House elderly care project under construction” (June 2011)**

**Wall Street Journal: “Nursing Home to Get New Style, Site” (December 2011)**

**Institutional Long-term Care Outside of the U.S.**

*Amsterdam: Multidisciplinary, Integrated Care Approach Improves Care*

A study focused on a multidisciplinary integrated care approach for 340 residents with physical or cognitive disabilities living in 10 residential care facilities near Amsterdam. About 10% of seniors aged 75 or older live in residential care facilities in the Netherlands, and more than 70% of residents have multiple chronic diseases and related disabilities. As part of the study, trained nurse-assistants conducted functional assessments every three months; discussion of priorities and outcomes with the family physician, patient and family members were held,
and monthly meetings with the patient’s health care team (including nurse assistant, family physician, psychologist and geriatrician) were conducted. The authors report that while functional ability, number of hospital admissions and health-related quality of life remained comparable (between the control group and study group), the model “resulted in substantially higher quality of care for elderly people in residential care facilities,” mortality decreased, and patients were more positive about the quality of their care. EurekAlert: "Multidisciplinary integrated care for seniors gives better quality care"

**Australia: Elderly Are Entering Nursing Homes Later, With Greater Care Needs**

An article in the *Sydney Morning Herald* highlighted a trend of elderly Australians entering nursing homes later in life and with greater care needs. The Australian government provides a subsidy for nursing home care for its citizens, and a recent forecast projects that the costs for this subsidy will increase $1.9 billion above the original forecast that was released in May. Robyn Batten oversees a non-profit organization that operates 4,500 nursing home beds and explained that the proportion of low-care patients has fallen in the past three years from 40% to 13%, which has also affected the staff at nursing homes. The median stay in nursing homes is about two years for women and one year for men, and Batten suggests that about 60% of patients also have some level of dementia. *The Sydney Morning Herald*: “Elderly more frail before moving to aged care”

**Scotland: Report: Hospitals In Wales Provide "Shamefully Inadequate" Care To Elders**

The Older People's Commissioner for Wales released a report in March 2011 and the Commissioner suggested that hospitals have considerable room for improvement in the care provided to elders, who represent 47% of inpatient admissions in 2009 and 2010. According to the report, avoidable incontinence happens regularly due to a lack of prompt response for calls for toileting assistance, a failure to prioritize toileting needs in care routines, and an over reliance on pads. Discussions of patient care are not always held in private, and care for patients with dementia can also be improved. Some patients also report positive experiences with doctors and ward leaders. The Commissioner's 12 recommendations include improving toileting, the discharge process, dementia care, and training for hospital staff. The Commissioner also recommends a pro-active approach to receiving patient and caregiver feedback, instead of only relying on complaints. *BBC*: "'Shameful' care of older patients in Wales, says report"

**Older People's Commissioner for Wales "Dignified Care?: The Experiences of Older People in hospital in Wales"**

**UK: Commentary Focuses on Enforced Relocation of Elder People**

A commentary in *Age and Aging* focuses on relocations for older people who are forced to move when care homes close or for other administrative purposes. The brief includes analysis on a recent court ruling in the United Kingdom about relocations and provides in-depth suggestions for practitioners to identify hazards in order to minimize risks when residents must be moved. Characteristics of residents who are most vulnerable during moves include: gender (men tend to do less well), age, dementia, depression, anxiety, and withdrawal in the face of relocation. When moves are inevitable, the authors advise informing residents and their families as soon as possible, making individual plans for each resident and sharing the information with all parties, and comprehensive medical and psycho-social needs assessments of residents with their families. *Age and Ageing*: "Enforced relocation of older people when Care Homes close: a question of life and death?" (article is free)

See Also:

*The Irish Times*: “Study finds elderly 'dread' going into home” (June 2011)

*The Telegraph*: “Dementia sufferers are being failed: report” (January 2011)

**Coverage of Family Caregivers in the Media**

Personal narratives from family caregivers not only raise awareness of family caregivers, but also humanize the many shortfalls in our nation’s long-term care and healthcare system in a way that reports and data don’t necessarily capture.

**ABC: Families on the Brink Focus on Elder Care**

*ABC World News* produced a television series focusing on the complex issues surrounding elder care. The panel discussions are available in print or video format, and address topics including elder drivers, medications and the stress of caregiving. Other topics discussed were Death and Illness: Having the Conversation, Nursing Homes and Other Options, and Elderly Driving: A Sign of Independence. *ABC News*: "Families on the Brink: What to do About Mom and Dad"
Adult Children Remodel Homes to Create Space for Parents
An Associated Press article highlights a trend of adult children remodeling their homes to create spaces for their parents to move in with them. The National Association of Home Builders reports that 62% of builders they surveyed were working on a home modification related to aging in 2010. A builder interviewed for the story suggested that involving the parents in the conversation with a builder will make a transition smoother. A company in Indianapolis, called Next Door Garage Apartments, can convert a two-car garage into a complete apartment within ten days for $35,000. A woman whose mother-in-law came to live with them explained that the arrangement works well because her mother-in-law doesn't need complex medical care, the family got along well before living together, and the mother-in-law pays for her portion of utilities each month, thus retaining some independence. Associated Press: "When an aging parent moves back in: tips for a smooth transition"

Brain Injury Documentary Airs on PBS Stations
Brain Injury Dialogues, a documentary about brain injuries, is airing on PBS stations around the nation during the month of March. The film's creators intend to bring greater awareness about brain injuries and the support available to brain injury survivors and their families. Brain Injury Dialogues

Caregiver Support Groups Frequently Asked Questions Answered
An article in the Herald Tribune by Paula Faulk, who directs a Caregiver Resource Center and Adult Day Service Program in Florida, explains the benefits of caregiver support groups and answers frequently asked questions. Faulk explains that in support groups, two rules are paramount: confidentiality and one person speaks at a time. New people will typically tell the group some information about themselves and their caregiving situation, and group members ask questions about their challenges. Faulk explains that these groups allow caregivers to learn from other members, speak without being judged, and be seen as a person separate from their care recipient. As trust between group members increases, they will help hold each accountable and encourage each other to identify options, build confidence, and take action. Faulk concludes by explaining that men are joining support groups in greater numbers and encourages readers to find disease-specific support groups. Herald Tribune: "Support groups a lifesaver for caregivers"

Caregiving: A Perspective from an 87-Year Old Mom on Boomers and Their Parents
A November column on Slate.com provides a unique view from the care recipient's perspective, in this case, from a mother to her baby boomer daughter. Lilian Rubin, the writer (and mother) explains that in response to her growing older, her daughter has increased the amount of phone calls she makes to her mom and has reduced her travelling abroad. A friend who reviewed the article highlighted the difficult issue of communication between parents and their adult children: "It would be nice if you'd expand on what you do need. Parents tend not to say what they need, and we children are left to try to figure it out, which leads to problems when we make mistakes." Rubin concludes: "At minimum, a change in Medicare policy that would allow for long-term care, whether outside or inside the home, without requiring that the recipient be impoverished - a policy shift that would ease the financial anxieties of both generations and surely assuage some of their psychological anxieties as well." Salon.com: "The dilemma of taking care of elderly parents"

“Explosion” of Baby Boomers
An episode of PBS NewsHour focused on the implications of some of the first of 79 million baby boomers turning 65 in 2011. Judy Woodruff interviews Ted Fishman, author of "Shock of Gray" and Nicholas Eberstadt of the American Enterprise Institute about some of the impacts including increased utilization of Medicare and Social Security. PBS NewsHour: "U.S. Faces 'Explosion of Senior Citizens': Will Baby Boomers Strain Economy?"

Is Lying To Parents Unethical?
The New Old Age blog addressed an issue faced by many caregivers: whether or not white lies are ethical. Paula Span, who wrote the blog posting, distinguishes between lying to a parent with dementia and lying to a parent who is stubborn, unwilling to stop driving, or unwilling to spend money they have saved. While two ethicists she interviews are mostly opposed to lying, some family caregivers responding to the blog posting supported fibbing, especially if they allowed a loved one to age at home, concerned driving safety, or were about the cost of a service. One family caregiver noted that "fibbing" can often be a two-way street, with parents insisting that they are okay to drive, or can handle the bills. NYT The New Old Age: "White Lies and Worse"

"Lives Worth Living” Chronicles History of the Disability Rights Movement
"Lives Worth Living," an independent film that chronicles the history of the disability rights community recently aired on PBS stations through the Independent
Lens series. The film uses oral history from activists to trace the history of the movement as it became increasingly vocal and active, culminating in the passage of the Americans with Disabilities Act in 1990.

LTC Ombudsman and Social Work Student Experience Living in Nursing Homes

Minnesota's Long-Term Care Ombudsman recently had first-hand experience of staying in a nursing home while recovering from shoulder surgery and while she was scheduled to stay for a week, she left after 25 hours. Deb Holtz explains that other than somebody offering her dinner, she sat alone for five hours after being admitted, without an admissions meeting. Right before bed time, a nurse entered her room to perform a skin check (to prevent bed sores), and despite Holtz explaining she didn't need the check because she was mobile, the nurse proceeded to check her exposed areas like her feet. The nurse stopped when Holtz told her to write on her chart that she had declined treatment, something she knew she had the legal right to request. Holtz was awakened the next morning by an aide turning on bright lights and telling her to stand up so she could be weighed. She ended her stay that day and explains that she felt a loss of dignity and that she felt more like a "check-mark on a to-do list." Star Tribune "Nursing home stay an eye-opener for advocate for elderly"

Kara Janes, a graduate student in social work in Maine, participated in a program called "Learning by Living," and through it, Janes spent ten days at a nursing home. As part of the program, Janes had a "diagnosis" of a stroke that disabled her right hand side as well as pneumonia because of an impaired ability to swallow. She fully embraced her diagnosis by being fed a pureed diet, being assisted with toileting, bathing in a whirlpool tub, and not having any visitors during her stay. While she applauds the staff and programs at the facility (which volunteered to serve as a host agency), she explains to the Bangor Daily News that the experience has still been challenging - "You lose your independence. You can't think for yourself. Everything is done for you." An administrator from the facility explains, "There's no place like home, but a busy in-house social calendar, regular shopping excursions and other "field trips" along with a cadre of dedicated volunteers help make Lakewood more livable." Bangor Daily News: "Long-term blues: UMaine student takes an insider look at nursing home care"

Middle Class Squeezed by Caregiving

Peter Bella, a retired Chicago Police Officer, wrote a column in the Washington Times about his experience caring for his 96-year old mother who has been living with him for the past six years. Bella explains: "The laws, regulations, and qualifications regarding home health care entitlements are confusing, contradictory, arcane, vague, and sometimes, arbitrary and capricious" and concludes that "If something is not changed, large numbers of us, or our children, will be faced with severe financial burdens or the dilemma of making quality of life choices that satisfy no one."

Washington Times: "The elderly dilemma: Medicare-Medicaid fail middle class families"

Navigating the Bureaucracy

An article written by Emma Wall chronicles the story of Daren Birch and his struggle to get appropriate care for his aunt who is in the advanced stages of Alzheimer's. Despite being told that his aunt needed an EMI (Elderly Mentally Infirm) home, she was placed in a residential care home without the proper support for a year. She was eventually moved to the appropriate setting, but he is still appealing decisions by the local government primary care trust to not pay for his aunt's care. The Telegraph: "Long term care: 'My aunt fell through cracks in the system"

NPR Show Discusses Value of Family Caregivers

NPR's "On-Point" show recently addressed the value of care provided by family caregivers, the stress caused by caregiving, and some of the additional costs borne by family caregivers. Susan Reinhard, one of the authors of AARP's recent report that found caregivers make 1.4 billion trips to doctor's offices every year. She suggested that trying to allow people to age in their homes is often dependent on family caregivers. Eileen DeGaetano, a caregiver who is also a nurse, explained that the care being provided is increasingly complex, and explained that having siblings and family members who participate has played a large role her parents remaining in their home. Christina Irving, a family consultant with Family Caregiver Alliance, explained that caregivers enter a new world with a lot of changes and a lot of uncertainty. She discussed the role of social workers who help caregivers navigate the many issues in long-term care. NPR On Point: "The Many Costs of Elder Care"
Number of Cohabiting Elderly Couples Triples during Past Decade
The *Sacramento Bee* reports that the number of Americans aged 65 and older who cohabitate has tripled from 193,000 in 2000 to 575,000 in 2010. The increase is tied to several issues, including greater societal acceptance of cohabitation without marriage, financial concerns, and a desire to not re-work legal documents like wills. Dr. Susan Brown, a professor who studies the topic, cites the example of a widow who currently receives her late husband's pension and/or health care coverage and who would be forced to forfeit that income if she were to remarry. *Sacramento Bee: "More Elderly Couples Live Together Without Marrying"

Sister-in-Law Shares her Experience as Caregiver in Video
*Kaiser Health News* released a video profile of Randol Brock, and his sister-in-law, Doris, who has been his primary caregiver since 1999. The profile is a touching and honest interview about the realities of caregiving. Randol had a high fever as a child that caused brain damage, and while doctors predicted he wouldn't live long, he is now 52 years old. Doris became Randol's caregiver in 1999 when his mother passed away. However, about three years ago, Randol's health declined and last December, Doris made the decision to move Randol to a group home. *Committed to Randol: One Family's Long Term Care Journey"

Wife of Veteran Writes about Experience with New VA Caregiver Program
Jennifer Conlon, the wife of a veteran who returned from two tours in Iraq as an infantryman in the Army, discusses her experience shifting from a wife to a caregiver in a posting on the VA’s blog, *VantagePoint*. She explains that when she heard about the VA’s new caregiver program for post 9/11 veterans, "I almost didn’t apply. I’ve been so used to not being taken seriously by people, friends and family included, about my husband’s condition." As part of the application process, nurses from the VA came to their house for a home visit. While she initially nervous, she explains: "The visit took thirty minutes at the most and again was enjoyable. I had more support and I felt so validated, finally, people believe me, they saw our struggles, they didn’t try to downplay anything, I didn't have to fight for help, I didn't have to plead my case, I didn't have to defend my husband’s condition or actions. Finally I wasn't alone anymore, finally I have a support system." *Vantage Point: "A Note from a Caregiver""

Workshop Gives Caregivers Perspective of Living with Alzheimer's
A workshop developed by a mental health nurse and drama therapist in the United Kingdom allows professional caregivers to experience some of the symptoms of Alzheimer's disease. During the workshop, "meal time" is simulated by asking participants to wear goggles to limit vision and gloves to limit mobility, while a colleague attempts to spoon-feed the participant quickly. Communication is simulated by asking participants to read the newspaper while colleagues ask questions rapidly and loud noises are played. An estimated 2/3 of adults in care homes in the UK have dementia, and the training has been implemented in nine care homes in the UK run by a health and social care services provider. The Nursing and Midwifery Council announced at the end of 2010 that future nursing students will be required to receive training in cognitive behavior. *BBC "Initiative helps dementia carers train in empathy"

See Also: *The Andover Townsman Online: VIRTUAL DEMENTIA TOUR: A peek at living with dementia*
Conclusion

While there were a number of positive developments in support of family caregivers during 2011, much work remains to be done. There is now a library of evidence that family caregivers take on enormous health, financial, emotional, and psychological risks.

There is also a strong foundation of evidence about “what works” in supporting family caregivers and their loved ones. In our last report, we noted that Pew Research Center population projections predict that 10,000 baby boomers will turn 65 every day for the next 19 years.

As the number of seniors increase, so too will the number of family caregivers, and so will their need for support in their roles.
“What you give... will come back to you. It will be me one day.”

— Ms. Crystal M.
Baton Rouge Caregiver


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