

HealthAffairs Blog

Family Caregivers: A Priority For Politicians?

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by Sean Coffey

A posting on the *Health Affairs* blog earlier this year by Carol Levine asked the pointed question: “[The year of the family caregiver- in what country?](#)” In it, she compared the “Year of the Family Caregiver” in the U.S. to the recent elections in Canada, where politicians were competing to see who could provide a more generous package of caregiver supports (including paid leave and tax credits) during an election year.

I thought about her column in updating our [legislation page](#) on our website with state and federal bills that affect family caregivers and their loved ones. While the breadth of bill topics, especially at the state level, (Alzheimer’s, family leave, long-term care insurance, elder abuse, workforce development, nursing home regulation, end-of-life care, and others) is impressive, fewer than half will likely be enacted.

Some of the laws already enacted in 2011 faced very little political opposition. For example, a law passed in Kentucky prevents people from receiving an inheritance from a person they have been convicted of financially exploiting, while another enacted law would prevent a person convicted of elder abuse from serving as a power of attorney.

But other laws have been far more contentious, like the recently enacted Paid Sick Leave in Connecticut, or the city-level Paid Sick Leave legislation approved by the Philadelphia City Council but vetoed by Mayor Nutter. While new laws supporting caregivers are important, the state budget is also where elected officials demonstrate whether or not supporting family caregivers is a priority.

In California, we’ve had a front-row seat to watch how a state slowly dismantles its long-term care system. Experts throughout the aging and disability world speak about the importance of shifting dollars away from institutional care and instead providing care where people want it — in their homes and community, which also happens to be cheaper for the taxpayer. This shift has been accelerated by the landmark *Olmstead* decision, progressive policymakers, people and organizations providing home and community-based services (HCBS) every day, family caregivers who provide care in conjunction with HCBS, and financial incentives from the federal government that are increasing with the passage of the Affordable Care Act.

Unfortunately, California appears to be going backwards, towards more costly, less desirable institutional care for folks who may not necessarily need it. *Stateline* noted the sad irony in Governor Brown starting the Adult Day Health Care (ADHC) Program during his first term in 1977 but then defunding the program in his third term. The plan in March was to continue ADHC with 50 percent less funding, but Governor Brown recently vetoed that plan as well, meaning that absent a court injunction, ADHC as we know it will end in December.

The *Stateline* author noted that ADHC has been a model for similar programs throughout the U.S. that serve an estimated 260,000 people, and that California could become the only state in the nation without an Adult Day Health Care program. Other programs serving family caregivers in California have also been reduced or face potential reductions later this year if state revenues don't meet rosy projections by December.

Why is it important if 2/3 of laws supporting caregivers are never enacted or if states are reducing budgets for programs that support family caregivers? There are three important reasons:

1) Money: Elected officials often cite a lack of money as the reason for cutting programs serving caregivers. This short-sighted view ignores a rather simple calculation, which is that community programs like Adult Day Health Care, respite, or home health care services are generally far cheaper than paying for a nursing home for somebody who could be better served with supportive services in their own home. A June report on [Ohio's long-term care system](#) captured this dynamic in looking at one of its Medicaid Waiver programs, PASSPORT, the third largest Medicaid waiver in the country. The program costs \$1,067 a month to provide in-home services to Medicaid beneficiaries, as compared to \$4,281 per month for nursing homes. A caregiver [commenting on the report](#) explained the importance of PASSPORT in her caregiving of her 80-year old mother: "To be able to make one call and know something can be taken care (of) for Mom – a piece of medical equipment, aide hours, paperwork, etc. – is priceless."

2) One Patient vs. Two Patients: There is a [substantial body of research](#) on the negative impacts caregiving has on the caregiver, including depression, increased risk of stroke, increased risk of dementia, chronic stress, and overall poorer health. Programs that support caregivers address some of these issues through respite, assistance with direct care in the home, adult day care programs, and other forms of support — thus ensuring that caregivers don't do this incredibly hard job on their own. When policymakers eliminate or reduce programs, they essentially ask these caregivers to take this job on by themselves. In many cases, this will eventually lead to the "two patient syndrome," where the care recipient and the caregiver are now both in need of care.

3) Impact on the Economy: The Family Medical Leave Act was progressive when it was passed 18 years ago. However, it is time for federal leaders to step up to the plate and make this program into a paid leave system, even if it's only 55 percent of salary, like California, or 66 percent as in New Jersey. As of right now, only [11 percent of American companies have volunteered](#) to offer paid leave to their employees. A [recent report](#) noted that 25 percent of adult children, mostly baby boomers, are serving as caregivers to their parents with an average financial impact of leaving the workforce early (to serve as a caregiver) of \$303,880 in foregone wages, Social Security, and pension benefits.

Without paid leave, caregivers are often left with the choice of quitting their jobs, or trying to juggle employment with caregiving. If they do quit, they take their institutional knowledge, skills, and relationships- all things that employers will have to invest in for new employees. [The recent firing of an employed caregiver](#) who requested a flexible schedule during his wife's cancer treatment should have been an alarm bell to elected officials everywhere. With more flexible scheduling and with paid leave, employed caregivers may not have to quit their jobs prematurely and companies would benefit from reduced turnover costs.

Why don't more laws supporting caregivers get enacted, and why are programs serving caregivers so often put on the chopping block? Part of it may be inertia in thinking about new ways to provide care- for example, Medicaid considering some programs (like nursing homes) mandatory for states while other programs (like

Adult Day Health Care programs) are optional. Another issue may be the fact that caregiving is a financially, emotionally, and psychologically demanding job and caregiving duties like making doctor's appointments, staying with somebody so they don't wander, or even doing household chores can mean very little free time. Meeting with an elected official may not be at the top of the list for a caregiver if they are lucky enough to have a few hours to themselves.

There may not be a good answer for how to increase support for family caregivers, but it would be wonderful if our 2012 presidential candidates were fighting to see who could provide a stronger support system for the nation's caregivers.