Keeping it Personal: Why All State Medicaid Programs Should Compensate Family Caregivers in Self-Directed Personal Care Services

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Second Place
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Introduction
On March 30, 2009, Mel sat down at his computer and typed into his online diary:

“Well, my name is Mel and I’m 80. My wife Joyce is 63. She has been diagnosed with Alzheimer’s. The only help I’ve received has been from my daughter who had a brain tumor, recently got married and is going to College. So there is a minimum of help. I tried a Bed and Care facility for a couple of months but my wife felt like a prisoner and made me take her home. I have been fortunate enough to find a Day Care that has accepted her for three days a week. My wife has been ill for the past three years. She is steadily losing more of her memory and capabilities. It has been very rough on me as her caregiver.”

He wrote about feeding, dressing, and changing his wife. He wrote about running the household by himself. He wrote about the stress of it all.

Mel is one of the nation’s over 40 million family caregivers, or unpaid relatives who care for their aging or disabled family members. As Mel’s story demonstrates, family caregivers provide the long-term care these elderly or disabled individuals would otherwise receive only in nursing homes and institutions. When these individuals choose to live in their communities rather than in nursing facilities, their physical or cognitive disabilities can sometimes hinder their ability to perform daily activities such as house cleaning or meal preparation, or Instrumental Activities of Daily Living (IADLs). Some disabilities even prohibit performance of such critical


daily tasks as eating, bathing, and grooming, or Activities of Daily Living (ADLs). Thus, many
turn to either personal care attendants from home health agencies or, increasingly, to family
caregivers to provide assistance.

While the elderly can purchase these services out of pocket or through long-term care
insurance, the Medicaid program, which shoulders 40 percent of the nation’s total long-term care
spending, also provides the benefit to its beneficiaries, many of whom are elderly or disabled. The Center for Medicare and Medicaid Services (CMS) designates personal care services (PCS)
as an optional Medicaid benefit, so states elect whether to cover the service. In states that do
cover it, individuals can use their Medicaid benefits to pay personal care assistants (PCAs) from
home health agencies.

But as Mel and Joyce illustrate, many individuals opt to receive assistance from unpaid
family members. About 43.5 million people, or 19% of the total United States population,
currently provide care for their family members or friends aged 50 and older. Despite their
performance of the same tasks as agency-hired PCAs, the federal Medicaid statute does not

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5 Id.

allow reimbursement for certain family caregivers.\textsuperscript{7} Family members deemed “legally liable relatives,” which includes legally-assigned caretaker relatives (which each individual state defines) and spouses, cannot receive Medicaid reimbursement if states elect to cover PCS in their state plans.\textsuperscript{8} However, depending on their state of residence, some elderly Medicaid beneficiaries fortunately escape this provision. States covering PCS in their state plans have the option to offer them through self-directed programs, in which individuals hire their own PCAs and direct their own care. States that offer self-directed PCS can choose whether or not to allow the beneficiaries to hire those legally liable relatives.\textsuperscript{9}

With the population over 65 expected to grow 89 percent from 2007 to 2030, situations like Mel’s will become even more frequent.\textsuperscript{10} The population age 85 or older, those most likely to create demand for long-term care, will grow 74 percent in the same time frame.\textsuperscript{11} Mel, who shared his story on the National Family Caregiver Association website, was seeking support and guidance from other family caregivers. In the coming years, these statistics show he will have plenty of company. His paid counterparts, PCAs from home health agencies, may not. Though the availability of direct-care jobs like personal care assistance is expected to rise 26 percent from 2000 to 2050, the population providing the care, usually women between 25 and 54 years

\textsuperscript{7} 42 U.S.C §1396n (2009).

\textsuperscript{8} 42 C.F.R. §440.167, 441.450 (2008).

\textsuperscript{9} 42 C.F.R. §441.478

\textsuperscript{10} AARP PUBLIC POLICY INSTITUTE, PROVIDING MORE LONG-TERM SUPPORT AND SERVICES: WHY IT’S CRITICAL FOR HEALTH REFORM (2009), http://www.aarp.org/research/ppi/health-care/health-costs/articles/fs_hcbs_hcr.html.

\textsuperscript{11} Id.
old, will grow only nine percent from 2000 to 2050.\textsuperscript{12} The supply of direct-care workers will not match the demand for their services. Family caregivers will become an even more critical part of the long-term care workforce.

On its website, CMS proclaims that it seeks to create a “person-driven” system where people “have choice, control, and access to a full array of quality services.”\textsuperscript{13} In denying reimbursement to certain family caregivers, state Medicaid programs do not fully support this mission. Experience shows that with proper (and simple) safeguards in place, the main critiques of family caregivers disappear. Policymakers in states that do not allow elderly Medicaid beneficiaries to hire legally liable relatives should re-examine their rationale, which is often prompted by fears of fraud and abuse and decreased quality of care. Otherwise, these states remain part of a disjointed long-term care system that not only deprives the elderly of truly independent choice but may soon face a severe supply and demand problem in the long-term care realm.

Part I of this paper examines the rise of PCS and its key role in the long-term care system, especially with the help of family caregivers. Part II follows the history of Medicaid payment for PCS to explore the social and political underpinnings of the current statutory provisions and the advent of self-directed PCS programs. Part III examines the policy reasons behind the Medicaid prohibition of family caregivers in PCS -- fraud and abuse, fear of creating


an unsustainable compensatory system, and quality of care arguments -- and offers safeguards and solutions to combat these fears. Part IV encourages policymakers in states that do not pay family caregivers to confront the tension between the implied moral duty of family caregiving and family caregiver compensation, examine their rationale for prohibition, and consider allowing all elderly Medicaid beneficiaries the choice to hire whomever they like.

**Part I: The Rise of Personal Care Services and Family Caregivers**

From its rise in popularity in the 1960s to its prominence today, personal care assistance has allowed elderly and disabled individuals to enjoy community life. Over the years, family caregivers have helped make this independence feasible, both physically and financially.

The Independent Living Movement arose in the 1960s proclaiming the idea that the disabled and cognitively impaired deserved the same civil rights -- especially the same decisional capacity over their own lives -- that the nondisabled enjoyed.\(^{14}\) It posited that society and culture, rather than the disabled themselves, must change to accept this ideal.\(^{15}\) Followers advocated for disabled individuals, a description which often includes the elderly, to assimilate into the community rather than remain isolated in institutions and nursing facilities.\(^{16}\) Such ideas


\(^{15}\) GINA MCDONALD AND MIKE OXFORD, EASTERN OREGON CENTER FOR INDEPENDENT LIVING, HISTORY OF INDEPENDENT LIVING (2010), [http://eocil.org/il-history.html](http://eocil.org/il-history.html).

\(^{16}\) Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), Part IV, 73 Fed. Reg. at 57,853.
followed the lead of contemporaneous social movements advocating for societal change. The civil rights advocates forced marginalized groups onto the national stage, while deinstitutionalization of the developmentally disabled showed the feasibility of community living. Likewise, the self-help movement was growing, which supported the idea that disabled individuals could direct their own lives, and the ideas of demedicalization, a movement focused on holistic health care, helped the Independent Living movement become a “paradigm of individual empowerment and responsibility for defining and meeting one’s own needs.” It promoted the use of home and community-based services (HCBS) to help the elderly and disabled maintain their independence.

Personal care services help make this freedom possible. Physical and cognitive disabilities may hinder one’s ability to live independently, but PCAs help erase those hurdles by helping the individuals perform ADLs and IADLs. Individuals obtain PCS either through public or private home health agencies (the “traditional” approach), with personal bank accounts, long-term care insurance, or Medicaid picking up the tab. Otherwise, unpaid family caregivers often perform PCS. This allows individuals to remain in their homes, an inviting prospect for the elderly. Just as Mel wrote that his wife Joyce “felt like a prisoner” in her nursing facility, a similar sentiment seems to echo among the growing elderly population. From 2000 to 2005,
the number of elderly and disabled adults receiving Medicaid-funded HCBS has increased over 34 percent, which means more and more people are seeking alternatives to institutional care.\textsuperscript{20}

One key alternative lies not only in PCS but in the use of family caregivers. Their growing prominence is clear. As of 2007, 34 million family caregivers provided these PCS for an economic value of $375 billion.\textsuperscript{21} Numerous national organizations exist to help family caregivers, all with extensive websites devoted to providing support and guidance.\textsuperscript{22} Legislation in the 111\textsuperscript{th} Congress saw 32 bills introduced that would in some way enhance the situations of family caregivers.\textsuperscript{23} The intimate nature of some personal assistance tasks, combined with care from a familiar face, makes it a comfortable alternative to hiring strangers. ADLs and IADLs often require hands-on, intimate interaction with the individual and his or her home. It is not difficult to see why many elderly individuals prefer a family member to help them on the toilet or to access their bank accounts rather than a stranger from a home health agency.

More importantly, the economic and financial state of the long-term care system also makes it easy to see why family caregivers will only grow in importance. Their services will prove essential to maintaining long-term care services for the aging population. Demand for

\textsuperscript{20} Houser, \textit{supra} note 2 at 14.

\textsuperscript{21} Houser, \textit{supra} note 2 at 31.

\textsuperscript{22} Some organizations include, among numerous others: National Family Caregivers Association (http://www.nfccares.org/ and http://www.thefamilycaregiver.org/); Family Caregiving 101 (http://www.familycaregiving101.org/); Family Caregiver Alliance (http://www.caregiver.org/); National Caregivers Library (http://www.caregiverslibrary.org/).

\textsuperscript{23} Email from Deborah Halpern, Communications Director, National Family Caregivers Association, to [name omitted for anonymity] (Mar. 10, 2010, 04:27 CST) (on file with recipient).
long-term care from the elderly will increase from eight to 19 million over the next 50 years, but the supply of direct-care workers will not match the demand.\textsuperscript{24} Though growth in the elderly population will prompt a 26 percent rise in direct-care worker jobs, which includes PCAs, the population providing the care will grow only nine percent from 2000-2050.\textsuperscript{25} Over 40 states currently experience worker shortages.\textsuperscript{26} Considering that these direct-care workers “are the primary delivery system for long-term care,” the aging population may have no one to take care of it.\textsuperscript{27} The problem becomes a disruption of simple equilibrium: the supply will not meet the overwhelming demand. Thus, family caregivers will fill the gap, level the equilibrium, and ensure the elderly get the care they need.

From a financial standpoint, rising demand for long-term care means rising expenses for Medicaid, the nation’s primacy financier of long-term care. The 2006 long-term care expenditures totaled $178 billion dollars. Medicaid picks up over 40 percent of this bill each year. Medicaid spending estimates from the Congressional Budget Office project that the federal share of Medicaid as a percent of GDP will increase from 1.5 percent in 2005, to 2.6 percent in 2035, and 4.8 percent in 2080.\textsuperscript{28} However, it is critical to acknowledge the bulk of this spending

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\textsuperscript{24} Department of Health and Human Services, \textit{supra} note 12.
\textsuperscript{25} Department of Health and Human Services, \textit{supra} note 12.
\textsuperscript{26} \textit{Paraprofessional Healthcare Institute and the Aspen Institute, Direct-Care Health Workers: The Unnecessary Crisis in Long-Term Care} 1 (2001), \textit{available at} http://www.directcareclearinghouse.org/download/Aspen.pdf.
\textsuperscript{27} \textit{Id}.
\end{flushright}
comes from nursing home care. At an annual average of $70,000 per bed, Medicaid paid 43 percent of the $124.9 billion spent on nursing home care in 2006.\textsuperscript{29} When considering that PCAs command less than $10 an hour (usually without benefits), the financial advantages of promoting home and community-based long-term care is obvious.

While not entirely equal when considering hours of care provided, a simple comparison of nursing home costs versus PCS costs shows the drastic financial difference. If Medicaid pays a PCA ten dollars an hour for 56 hours a week (eight hours a day, seven days a week), this totals only about $29,000 a year, compared to $70,000 a year per nursing home bed. The Association for the Advancement of Retired Persons estimates that on average, “Medicaid dollars can support nearly three older people and adults with physical disabilities in home and community-based settings for every person in a nursing facility.”\textsuperscript{30} While dollars spent on HCBS and nursing homes are not identical, given the differences in room, board, and around-the-clock care, in general Medicaid spends significantly more on nursing home facilities than on HCBS.\textsuperscript{31} Thus, the more service family caregivers can provide in the home means the less Medicaid pays in nursing home costs. Conversely, the less care family caregivers provide means Medicaid pays more in nursing home costs.\textsuperscript{32} A system cannot run without money; Medicaid cannot fulfill its mission without money to operate.

\textsuperscript{29} The Henry J. Kaiser Family Foundation, \textit{supra} note 4.

\textsuperscript{30} Houser, \textit{supra} note 2 at 17.

\textsuperscript{31} Houser, \textit{supra} note 2 at 17.

\textsuperscript{32} The Henry J. Kaiser Family Foundation, \textit{supra} note 4.
Society has embraced PCS as an alternative to institution-based care, and this alternative will only grow in importance as the population ages. The PCS that family caregivers provide is financially beneficial for the long-term care system at large and personally valuable to the fortunate recipients of this care.

**Part II: An Analytical Chronology of Medicaid Payment for Personal Care Services**

The evolution of HCBS over the years shows national recognition of its importance in the long-term care system. Moreover, the evolution shows an increased willingness to pay for family caregivers. Looking at the chronology of PCS is vital to understanding the problem at hand: why do some states embrace family caregivers and others shy away?

While family caregivers prove to be an inexpensive, valuable option for elderly Medicaid beneficiaries, the traditional Medicaid program does not make this setup an easy one. The Medicaid statute defines personal care services as:

> “Services furnished to an individual who is not an inpatient or resident of a hospital, nursing facility, intermediate care facility for the mentally retarded, or institution for mental disease that are A) authorized for the individual by a physician in accordance with a plan of treatment or (at the option of the State) otherwise authorized for the individual in accordance with a service plan approved by the State, B) provided by an individual who is qualified to provide such services and who is not a member of the individual’s family, and C) furnished in a home or other location.”

This provision prohibits compensation for family caregivers providing PCS. Defined as “legally liable relatives,” these family members are individuals who have a duty under state law.

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33 42 U.S.C. §1396d.
to care for another person, including legally-assigned caretaker relatives and spouses. This prohibition applies in the 31 States, including Washington D.C., that only cover PCS through their state plans.

But a new idea emerged in the 1990s: self-directed care. A model formed on the ideals of the Independent Living Movement, self-directed care is a “service delivery mechanism that empowers individuals with the opportunity to select, direct, and manage their needed services and supports identified in an individualized service plan and budget plan.” An alternative to traditional agency-directed models, it casts the elderly individual into the role of employer with the power to hire, fire, train, and supervise a PCA of his or her choosing. Self-directed plans embody the ideals of the Independent Living Movement and posit that “physical (and even cognitive) limitations should not be barriers to expressing preferences and making decisions about the services they receive and about how they conduct their lives.” Through the self-directed program, the beneficiary engages in a “person-centered process…[that] builds upon the

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34 42 C.F.R. §440.167.


36 Medicaid Program; Self-Directed Personal Assistance Services Program State Plan Option (Cash and Counseling), Part IV, 73 Fed. Reg. at 57,853.

37 Id.

individual’s capacity to engage in activities that promote community life and that respects the individual’s preferences, choices, [and] abilities.”39

As the Robert Wood Johnson Foundation awarded various grants throughout the decade to states willing to try the self-directed programs, the success of the idea became apparent. Participants reported fewer unnecessary institutional placements and unmet needs while experiencing higher levels of satisfaction and higher continuity of care because of less worker turnover. Self-directed programs “maximized the efficient use of community services and supports.”40 In particular, Cash and Counseling, a self-directed demonstration project under section 1115 waiver authority, flourished in Arkansas, Florida, and New Jersey in the late 1990s. Seeking to compare the self-directed model with the traditional agency-directed model, Cash and Counseling proved so successful that it expanded with the aim of establishing self-directed programs in every state’s Medicaid program. Currently, 15 States use the general Cash & Counseling model under various names.41

Continuing the national attention to HCBS, then-President George W. Bush announced the New Freedom Initiative a mere 12 days after inauguration, a testament to the importance of community-based care. The initiative aimed to develop “a government-wide framework” for elderly and disabled individuals to fully engage in their communities.42 President Bush’s June 18, 2001 Executive Order said it best: “The United States is committed to community-based

39 42 U.S.C §1396n.

40 Medicaid Program, supra note 36.

41 Id.

42 Medicaid Program, supra note 36 at 3.
alternatives for individuals with disabilities and recognizes that such services advance the best interests of Americans.\textsuperscript{43}

Aligning with this new national agenda and armed with glowing reviews of self-directed programs, the Department of Health and Human Services (DHHS) implemented its Independence Plus initiative in May 2002. This initiative made it simpler for states to offer the self-directed services that had fared so well in the national pilot projects of the 1990s by creating waiver templates for states to follow. First, DHHS created the section 1115 demonstration waiver template that allowed states to develop self-direction programs wherein participants managed their cash allowance prospectively while directing their PCS purchases.\textsuperscript{44}

Second, DHHS offered the 1915c HCBS waiver template to states that did not want the cash allowance option. This allowed Medicaid recipients to self-direct virtually any PCS required to delay placement in a nursing facility or institution.\textsuperscript{45} With an overarching goal of integrating the elderly and disabled into the community, the Independence Plus initiative sought to delay or avoid institutionalization by bolstering support to individuals and their families and encouraging solutions to long-term care workforce shortages.\textsuperscript{46} Thus, the waiver templates created a quicker, more streamlined way for states to recognize the independence of their elderly and disabled citizens while also saving money and strengthening the workforce.


\textsuperscript{44} Id.

\textsuperscript{45} Id.

\textsuperscript{46} Id.
At this point, it is critical to understand how these waivers play out for the Medicaid beneficiaries. First, a 1115 waiver allows states to test experimental, pilot, or demonstration projects that implement new policy and promote Medicaid objectives.  

States applying for this waiver craft a proposal, subject to CMS approval, that details the environment, administration, eligibility, coverage and benefits, delivery system, access, quality, financing issues, systems support, implementation time frames, and evaluation and reporting of the pilot program. Compensation for legally liable relatives may or may not be included in a state applying for a 1115 waiver to test a self-directed PCS program.

States encounter a similarly extensive process in applying for 1915c HCBS waivers to provide HCBS to individuals choosing to live in the community who would otherwise require institutional care. States can use the waiver, subject to CMS approval, to provide services that they do not, or otherwise could not, offer in their state plan or to increase the amount of services already offered. For PCS, states apply for this waiver to start a self-directed program. True to the spirit of consumer choice, states with a 1915c waiver may -- but are not required to -- permit the hiring of legally liable relatives.

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47 Centers for Medicare and Medicaid Services, Research and Demonstration Projects – Section 1115, http://www.cms.gov/MedicaidStWaivProgDemoPGI/03_Research&DemonstrationProjects-Section1115.asp (last accessed May 16, 2010).

48 Center for Medicare and Medicaid Services, Medicaid HCBS Waivers – Section 1915c, http://www.cms.gov/MedicaidStWaivProgDemoPGI/05_HCBSWaivers-Section1915(c).asp (last accessed May 16, 2010).

49 Id.

50 Robert Wood Johnson Foundation, supra note 3 at 1-10.
But this nod to family caregivers comes at the expense of the time and energy invested in obtaining a waiver. Although streamlined into a waiver template, the application process is a rigorous one. States must demonstrate the aggregate cost-neutrality of their programs and “describe in detail the critical operational features of their waivers,” including service quality assurance and management. The waiver application must also detail how it will inform potential participants of the benefits, consequences, and responsibilities in self-directed programs; how it will offer financial management, and individual budget management, services for its participants; how the state will provide assistance to participants, such as counseling or case management; how the state will transition beneficiaries into the self-directed program; and the circumstances for a beneficiary wanting to terminate participation in the self-directed option.

The end result of all this work can prove fruitful for family caregivers: waivers give the state the option of reimbursing family caregivers, including legally liable relatives. Thus, for beneficiaries living in states with waivers that include legally liable relative compensation, family caregivers get the recognition they deserve. But because the state must opt for it, the benefit is a tenuous one. For the elderly Medicaid beneficiaries unfortunate enough to live in states that have not opted for legally liable relative reimbursement, they must hire strangers to fulfill their PCS needs.

With this rich, energetic history propelling it forward, 2005 legislation recognized the importance of self-directed programs when Congress included the model in its Deficit Reduction

\footnote{Id. at 2-16.}

\footnote{Id.}
Act of 2005 (DRA). The DRA amended the Social Security Act to give states a self-directed option with prospective cash disbursement for PCS that followed the Cash and Counseling model.\(^{53}\) Like the self-directed programs previously discussed, it authorized individuals to “to exercise choice and control over the budget, planning, and purchase of self-directed [PCS], including the amount, duration, scope, provider, and location of service provision.”\(^{54}\) Although still subject to Secretary approval and numerous regulatory requirements, the DRA simplified the process for states to offer PCS, as it eliminated the need for them to obtain demonstration waivers for self-directed programs. The self-directed program had grown from a demonstration project to a bona fide model for PCS delivery.

However, what the DRA eliminated in waiver requirements, it replaced with regulations calculated to assure the utmost in participants’ physical and financial safety. Overall, the states electing self-directed services under the DRA must meet five assurances for Secretarial approval. The state’s self-directed program must provide necessary safeguards to protect the health and welfare of participants while also assuring financial accountability for funds used.\(^{55}\) States must also demonstrate they will conduct an evaluation of need for PCS and assure that eligible individuals know of their alternative choices for long-term care.\(^{56}\) They must develop a support system that guarantees the assessment and counseling of participants prior to their enrollment, as

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\(^{54}\) Medicaid Program, supra note 36 at 2.

\(^{55}\) Id.

\(^{56}\) Id.
well as participants’ ability to manage their budgets.\textsuperscript{57} Finally, states must establish a way to report annual participant and expenditure data to the Secretary, as well as the overall impact of self-directed PCS on participants’ health and welfare compared to those participating in traditional agency-directed PCS.\textsuperscript{58}

Most importantly, the DRA gives states the option to compensate “any individual capable of providing the assigned tasks” as PCS providers, including legally liable relatives.\textsuperscript{59} The final regulations define “legally liable relatives” as “persons who have a duty under the provisions of State law to care for another person,” which may include legally-assigned caretaker relatives and spouses.\textsuperscript{60} Public comments on the Notice of Proposed Rulemaking suggested modifying the definition of “legally liable relatives” to include significant others, specific training requirements, and other supposed safeguards. However, the final regulations left these modifications up to the states. It reasoned that expansion would infringe on the purpose of the programs: “One of the most valued aspects of a self-directed program is that participants have the authority to train their providers…in what they need and how to deliver the [PCS] in accordance with their personal, cultural, and religious preferences.”\textsuperscript{61}

Tracking the history of PCS and the development of the self-directed model shows its growth from demonstration project to recognized model of care delivery. As of 2010, states can

\textsuperscript{57} Medicaid Program, \textit{supra} note 36 at 2.

\textsuperscript{58} \textit{Id.}

\textsuperscript{59} 42 C.F.R. §440.478 (2008).

\textsuperscript{60} 42 C.F.R. §441.450 (2008).

\textsuperscript{61} Medicaid Program, \textit{supra} note 36 at 10.
deliver PCS to Medicaid beneficiaries through three main avenues: covering them through a state plan (whether through the traditional model or through a self-directed model per the DRA); covering them through a 1915c HCBS waiver; and finally, covering PCS through a 1115 demonstration waiver. While all options give elderly Medicaid beneficiaries the opportunity to remain independent in their communities, many states choose avenues that make it difficult or impossible for those beneficiaries to hire and pay legally liable relatives as PCAs. With the traditional state plan prohibiting their compensation, and the other avenues merely giving states the “option” to allow the hiring of legally liable relatives, what results is a disjointed “system” of PCS that disadvantages different elderly Medicaid beneficiaries depending on their state of residence. Thus, these individuals lose the whole purpose of self-directed care: they lose the ability make their own decisions about their healthcare and ultimately, their lives.62

In the end, there are truly only two circuitous ways an elderly individual can hire a legally liable family member. In one scenario, the beneficiary lives in a state that covers PCS in its state plan, has elected the self-directed program under the DRA, and has opted to allow payment to legally liable relatives. In the other scenario, the beneficiary’s state has secured a 1915c or 1115 waiver and has opted to allow payment to legally liable relatives. In 2008, 41 percent of states that covered PCS in their state plans allowed self direction, while 71 percent of states using waivers allowed self direction in at least some of their waivers.63 Thus, in making

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payment for family caregiving difficult to attain (depending on the beneficiary’s state of residence), the long-term care system loses not only potential workers but also a less-expensive source of care, both of which will help to quell the effects of an aging population.

Part III: Policy Reasons Behind the Prohibition

Arguments abound in support of Medicaid’s family caregiver prohibition: possibilities of fraud and abuse, Medicaid’s inability to afford their salaries, and a decline in quality of care. However, the inherent safeguards in self-directed programs, along with their corresponding federal regulations, combat these potential problems. Various programs around the country have shown that allowing family caregivers helps, rather than hinders, the quality of both the individuals’ care and the Medicaid program at large.

Fraud and Abuse

Critics argue that compensating family caregivers promulgates fraud and abuse. They fear the situation is ripe with ways family members can cheat the system and harm elderly beneficiaries. With decreased cognitive capacity generating a susceptibility to abuse, the prospect of paychecks can drive family members to force elderly beneficiaries into electing self-directed services rather than alternatives such as nursing homes. Similarly, the family member holds bargaining power over the individual if he or she “is fearful of losing support and is threatened with nursing home placement and so signs for receipt of services.”

Fraud can also occur when a relative, acting alone or in conspiracy with the beneficiary, collects payments for

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services not rendered. Consequently, the state pays for sub-standard care (or care not provided at all), and the elderly beneficiary suffers.

However, the situations described here differ little from those in other long-term care settings. Fraud and abuse do not necessarily stem from the caregiver’s blood relationship to the elderly individual. In her 2007 testimony to the U.S. Senate Special Committee on Aging, Beverly Laubert, President of the National Association of State Long-Term Care Ombudsman Programs (NASOP), stated the following: “Every day of my twenty years as a long-term care ombudsman I have been touched by the bravery of residents and families who entrust their care to strangers.”

Bravery? The statistics prove her point. A 2001 study of 247 home health care fraud cases over the period of 1993-2000 found 30 percent of those cases involved PCAs. Billing for services never rendered composed 66.8 percent of all the cases, while forgery accounted for 30.4 percent. Most were repeat offenders against Medicaid.

Abuse arises outside the home as well. For most PCS users, the alternative is nursing home care rampant with well-documented abuse. In 2005, NASOP collected 91,974 reports related to abuse, neglect, and exploitation. Abuse included, among other types, physical,

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65 Long-Term Care Workers and Abuse of the Elderly: Hearing of the U.S. Senate Special Committee on Aging, 110th Cong. (July 18, 2007) (statement of Beverly Laubert, President, National Association of Long-Term Care Ombudsman Programs), available at http://www.nasop.org/papers/Policy3.pdf.


67 Id.

68 Long-Term Care Workers and Abuse of the Elderly: Hearing of the U.S. Senate Special Committee on Aging, supra note 66.
sexual, verbal/mental, financial exploitation, and gross neglect. 69 Clearly, nursing homes are not necessarily safer than the alternatives.

In any case, the regulations mandate numerous safeguards in self-directed programs. Although they leave the details to state discretion, the broad ideas still protect the elderly. States must install necessary safeguards not only to protect individuals’ health and welfare but also their finances.70 They must create a support system that meets the following requirements: first, it assesses and counsels individuals before enrollment; and second, it provides specific requirements for providing the individuals with counseling, training, and other assistance to enable them to manage both their PCS and budget. 71 To ensure that elderly beneficiaries truly want PCS, the regulations require that states provide beneficiaries with information about feasible alternatives (such as agency-directed care) “in a manner and language understandable to the individual” that assures timely, informed decision making.” 72 When someone monitors the individual’s holistic situation, it is harder for fraud and abuse to occur.

Having case management-type safeguards also ensures that participants have the cognitive capacity to self-direct their PCS. States must cover the traditional agency-directed PCS in their state plans or waivers, so that participants can un-enroll at any time.73 Also, states must provide an “assessment of the needs, capabilities, and preferences of the individual,” so

69 Id.


71 Id.

72 Id.

73 42 C.F.R. §441.452.
case managers can screen out those lacking the requisite cognitive capacity.\textsuperscript{74} Even if individuals lack full capacity, they still have the option to appoint a representative who directs the PCS in their stead.\textsuperscript{75} Permissible representatives include those recognized under state law to act on behalf of incapacitated adults and state-mandated representatives (subject to CMS approval and only when demonstrated that, after counseling, training, or other assistance, the individual cannot direct his or her own care).\textsuperscript{76} Most importantly, the regulations prohibit the representative from playing a dual role as PCA. The representative acts solely on behalf of the cognitively-impaired elderly individual, which lessens the opportunity for exploitation.

States using self-directed PCS programs show how the general safeguard requirements unfold in real life. In the 15 states using the Cash and Counseling model, beneficiaries receive counseling services that help identify and addresses potential conflicts of interest, review and approve spending plans, and ensure that participants remain involved in all aspects of their care.\textsuperscript{77} The counselors instruct participants as to their rights and responsibilities while assessing their problem-solving and decision-making skills.\textsuperscript{78} Because these counselors follow participants throughout their program tenure, they can catch fraud and abuse in action.

States offering PCS through waivers use similar protections. The key safeguard in Colorado’s program, which operates under a 1115 waiver, is case management. Case managers assist with referral, intake, screening, support management planning, prior authorization, 

\textsuperscript{74}42 U.S.C. §1396n.

\textsuperscript{75}42 C.F.R. §441.480.

\textsuperscript{76}Id.

\textsuperscript{77}Cash and Counseling, supra note 42.

\textsuperscript{78}Cash and Counseling, supra note 42.
monitoring, and reassessment. Similarly, Montana’s program, implemented through a 1915(c) Independence Plus waiver, also employs case managers and counselors called Independence Advisors. These trained and certified workers provide ongoing support, consultation, resources, and training information to beneficiaries and help them develop their service and spending plans. A common thread across these programs lies in ensuring that individuals know their rights and have numerous outlets through which they can express concern.

Long-term care scholar Andrew Batavia writes that concerns about cognitive capacity embody “paternalism deeply ingrained in the service delivery system.” It is a “misconception based in part on a cultural phenomenon referred to as the ‘elderly mystique,’ the belief that elderly people are inherently dependent and need others to manage their lives.” Self-directed programs aim to dispel this mystique, and the safeguards discussed here assist in this goal. Although programs could never prevent all fraud and abuse, the rigorous monitoring of self-


directed programs provides beneficiaries with a safe system working to ensure they receive the best possible personal care.

The “Woodwork Effect”

Even if these fraud and abuse safeguards do succeed, critics fear another problem lurks in the background. Those opposing family caregiver reimbursement cite the “woodwork effect,” or the fear that if Medicaid requires states to reimburse all family caregivers, droves of current (and prospective) caregivers will emerge to claim the benefits and create an unsustainable payroll.83 One source projects that compensating just the current 43.5 million informal family caregivers alone could increase costs by as much as five times.84 The argument seems logical: if Medicaid offers compensation, family caregivers, both current and prospective, will line up for paychecks. If Medicaid increases its payroll, it will spend more money.

Various factors belie this scenario. First, these estimates of the prevalence of informal caregiving make accurate budgetary predictions easier.85 While this does not guarantee the solvency of the Medicaid bank account, it does assuage the concern of the woodwork effect because while some caregivers may emerge from the shadows to claim checks, it is generally not anyone Medicaid does not (generally-speaking) already know is there. New family caregivers will certainly enter the mix, but states can plan at least for those who already provide free care to their elderly family members. Furthermore, counselors assess care already provided, and


84 Blaser, supra note 65.

85 National Alliance for Caregiving, supra note 6.
support systems already in place, when forming care plans in self-directed programs. Family caregiver compensation does not increase the need for personal care because Medicaid already entitles individuals to the benefit. Rather, it just recognizes care already taking place.\footnote{Cash and Counseling FAQ, \url{http://www.cashandcounseling.org/about/FAQ}.}

Second, the “woodwork effect” naturally assumes family caregivers will jump at the chance for payment. But the theory fails to account for a major factor: the meager wages PCAs earn. The national mean hourly wage for personal and home health aides of $9.47 (or less than $20,000 a year) virtually ensures that few will quit their day jobs to take on family caregiving as a sole source of income.\footnote{Bureau of Labor Statistics, Occupational and Employment Wages May 2009, 39-9021 Personal and Home Care Aides, \url{http://www.bls.gov/oes/current/oes399021.htm} (last accessed May 16, 2010).} The fact that PCAs generally provide more hours of care than their paychecks show makes the wages even more unappealing.\footnote{Cash and Counseling, \textit{supra} note 42.} Thus, some in the “woodwork” might not even emerge at all. Even if some do choose family caregiving over their former jobs, administrators and policymakers of state self-directed programs could implement hour limits and thus fix the amount the program will pay to family caregivers every year. While new caregivers will likely enter the system, an hour limit would help to protect against the budgetary explosion that worries critics. It will also add to the array of meetings with program counselors, background checks, and other paperwork a prospective caregiver must complete (depending on the state requirements) before receiving payment. A meager salary combined with an extensive planning process will temper the urges of many to line up for compensation.
To prevent the “woodwork effect,” a state can strategically make the compensation process, though efficient, just taxing enough to weed out those with ill intentions. Combined with a salary that essentially just recognizes the care provided rather than actually compensating for every hour worked, these safeguards make it possible for legally liable relatives to enter the Medicaid provider pool without draining the state and federal budgets.

Quality of Care

The idea of creating a compensation process with hurdles to catch potential abusers already exists somewhat in training and licensure programs. But because family caregivers are not trained and licensed in direct-care work, the concern arises about the quality of their services. Training and licensing can help promote quality in several ways. They eliminate the incompetent from the workforce, give professional oversight to the standards of quality, and help patients ill-versed in healthcare select their best provider. These requirements ensure the mastery of task performance and also help to screen out those not mentally or physically prepared for the PCA role. Consequently, this protects the elderly by screening for quality providers.

But licensing and training are not always harbingers for quality, especially in the personal care realm. The volatile turnover in the direct-care workforce, combined with the patchwork requirements that vary among (and even within) states, suggests that training and licensure are not as important in this realm as other facets. Personal care involves non-technical, generally

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non-medical tasks that prompt a new definition of quality for PCS -- one that focuses on consumer satisfaction.

Training and licensure requirements differ across and within states, which suggests that a certificate of completion or a log of hours in a classroom does not necessarily guarantee success on the job. Many state programs do not even require PCS training regardless of the program model. A Health and Human Services/Office of Inspector General report compared state Medicaid PCA requirements and qualifications. The report found that, in contrast with other direct-care professions where states have established standard sets of requirements, 43 states had multiple sets of requirements for attendants. The six most common ones (background checks, training, supervision, age, health, and education/literacy) had differing definitions and applications across the states. For instance, one state had different requirements in its state plan for the agency-directed and self-directed programs, as well as its waiver program agency-directed and self-directed models. But regardless of the model in which they work, all PCAs complete similar tasks. If classroom training were of critical importance to the job, the requirements would be more standardized like in other lines of work. Even if experience begins to show the benefits of classroom training, implementing a short training and licensure program would not unduly burden states. They have plenty of models from which to work.

The criminal background check provisions in Patient Protection and Affordable Care Act of 2010 will also help with one area that definitely could affect quality: the prevalence of background checks. The Act requires the Secretary of Health and Human Services to establish a

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90 Levinson, supra note 28 at 8.

91 Id. at ii.
nationwide program “to identify efficient, effective, and economical procedures” for long-term care facilities and providers to conduct background checks on prospective direct-care providers, including PCAs. While it does not mandate states’ participation, it incentivizes involvement by offering federal funding for states that comply.\textsuperscript{92}

But discussions of overall quality prompt a larger issue: because personal care is not medical care in the traditional sense, it is inappropriate to apply the medical definition of quality to these services. Aside from simple first aid or other minor medical tasks, most of personal care training involves ADL and IADL review, basic health facts (blood-borne pathogens, hygiene, and nutrition), and general job orientation (confidentiality and safety). Disjointed and ill-defined requirements make it harder to measure and assess quality. The healthcare realm tends to define quality in terms of procedural efficiency and effectiveness as well as outcomes, measurable with data and statistics. But quality in personal care is not so tangible. It arises when the PCAs work promotes the individual’s quality of life and consumer satisfaction. Here, family caregivers shine. In the self-directed plan, beneficiaries exercise choice and control.\textsuperscript{93} Because the individual sets the terms and requirements of employment, each person will have a unique definition of “quality” care. Subjecting family caregivers to training requirements only because of a claim that it promotes (an inappropriately-defined) quality of care hinders elderly individuals’ ability to remain independent and part of their communities. The intimacy of personal care tasks is striking. Strangers enter someone’s home and perform daily tasks that


\textsuperscript{93} 42 C.F.R §441.450.
individuals have lost the capacity to complete. Because they come from the same family, culture, religion or other important background, family caregivers are in a better position to know the personal and intimate needs of an elderly family member.\textsuperscript{94}

The individual’s role of employer in self-directed programs also dispels the argument that training and licensure bridge the knowledge gap between provider and patient. In a self-directed system, individuals assert what they want. A knowledge gap does not exist; or rather, it exists in reverse: with non-family member PCAs, it is the provider (PCA) who may not understand the patient’s (Medicaid beneficiary’s) desires. They lack the inherent “interpersonal competence” a family member is more likely to have.\textsuperscript{95} The Notice and Comments for the DRA regulations stated that it left provider restrictions somewhat open to state modification because “the focus should be on whether the worker is qualified to furnish the service in the service plan according to the participant’s personal, cultural and religious preferences.”\textsuperscript{96} While easy to cling to the quality of care argument, the comments state that “professional oversight may be unnecessary for services that are intimate and personal and only minimally medical or technical.”\textsuperscript{97} Individuals’ decision-making authority under the PCS program includes training their own PCAs or requiring other training as desired.\textsuperscript{98} Thus, policymakers do not judge quality of performance -- the care recipient does.

\textsuperscript{94} Simon-Rusinowitz, \textit{supra} note 84.

\textsuperscript{95} Benjamin, \textit{supra} note 38 at 89.

\textsuperscript{96} Medicaid Program, \textit{supra} note 14.

\textsuperscript{97} Benjamin, \textit{supra} note 38 at 89.

\textsuperscript{98} 42 C.F.R. §441.450.
If states decide training and licensure, though not guarantees of safe and effective care, nevertheless play a crucial role in PCS, they must keep this separate definition of quality in mind when promulgating requirements. When combined with the self-direction program ideals, and the regulations which support them, states can create programs that offer compensation to family caregivers without worry.

**Part IV: The Solution**

The factors discussed above not only prove family caregivers capable of providing PCS, they prove them essential to a long-term care workforce that can sustain an aging population. In states that do not reimburse for family caregivers, policymakers must examine the rationale for this prohibition. The aforementioned safety and economic concerns certainly play a role. But economic arguments do not address the deep-seated notion inside many of us -- the notion of personal responsibility, or the queasy feeling that arises when thinking about accepting a paycheck for bathing our mothers, just like they did for us as children (sans paycheck). Out of this feeling can arise a reluctance to pay family caregivers.

The moral duty we feel is an implied one. No legal duty requires children or other kin to care for their elderly relatives.\(^99\) Policymakers must consider whether paying strangers to care for our loved ones, whether in nursing homes or using PCS, is really a better (that is, a “moral”) alternative to compensating family members for the physically and emotionally draining work of being a family caregiver. Medicaid payment merely recognizes that services rendered can burden a family. It does not erase the responsibility or the implied moral duty of caring for one’s

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family. If anything, a person discharges this duty by entrusting his loved ones to strangers. Of course, becoming a caregiver is not always physically, emotionally, or financially possible, but when one does accept small compensation, this is not an avoidance of personal responsibility. It is assuming that responsibility in full force. Medicaid programs that prohibit family caregivers must step back and assess the evidence. Experience proves the value of family caregivers. It dispels many economic arguments, and it can erase that queasy feeling.

Part V: Conclusion

From their advent, self-directed personal care services have played a dual role for elderly Medicaid beneficiaries in allowing them to assert their independence and make their own choices while remaining in their homes. But due to the Medicaid statutory provision that only gives states the option, rather than a mandate, to cover family caregivers, elderly individuals in various states lose the option of hiring legally liable relatives who might be the exact provider they want. When the DRA authorized compensation for legally liable relatives, policymakers recognized family caregivers as important PCS providers. The aging population ensures that the prominence of family caregivers will continue to grow and keep the long-term care system afloat. With proper safeguards in place, experience allays the fears common amongst critics of self-directed care. Once a state installs these safeguards, its policymakers should re-examine their evidence against family caregivers and consider legally liable relatives as viable providers of long-term care. Otherwise, these states may not only face a shortage of long-term care workers but also deny their elderly beneficiaries the independence, and the dignity, of free choice.
More from Mel’s online diary illustrates this well:

“My assets are dwindling. Savings account is lowering… a fear of losing everything has been very frustrating… For now I have taken over everything. I do it all alone…My love for her and her love for me is still strong and keeps me going. I promised to see that she is taken care of.”

Now, states need to make sure Mel gets taken care of, too.

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100 National Family Caregiver Alliance, supra note 1.