Funding Kinship Care: A Policy-Based Argument for Keeping the Elderly in the Family

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Joe and Eileen* are octogenarians who have been married for more than sixty years. They are both currently in quite good health, though past episodes of bad health have limited their ability to perform some household tasks, like mowing the grass and scrubbing the bathroom. They sold their home about two years ago at the insistence of their son, who was frustrated because Joe—chronically unhappy with the lawn service hired to keep him from doing yard work—insisted on re-mowing behind the service every time they visited. Joe’s son worried Joe would fall and re-break the hip he shattered several years ago, or even suffer a heart attack or stroke while mowing.

Joe and Eileen relocated to a two-bedroom apartment nearer to their son’s house, and they call on him periodically to help them with groceries and other errands. Joe’s driver’s license has been revoked, but Eileen still drives; she just prefers not to go out after dark, and because her son is handy, she calls him instead. Their son, somewhat short-tempered, divorced, and the owner of a business, resents his parents’ demands on his life. Their increasing vulnerability shakes him up more than he would admit.

Having recently discovered his parents’ bathroom in a less than pristine condition, he has decided that they are no longer fit to live on their own. He is demanding that they relocate once again, this time into an assisted-living facility* where they will share a small one-bedroom apartment and have all of their needs met by the staff. They do not want to go, but their son and his brother are insisting.

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1. The stories of Joe, Eileen and Mary have been fictionalized, but are based on the experiences of family and friends of the author. Their names have been changed to protect their privacy.

2. See generally Stephanie Edelstein, Assisted Living: Recent Developments and Issues for Older Consumers, 9 STAN. L. & POL’Y REV. 373 (1998) (discussing the legal issues attending assisted living arrangements and advertising). Edelstein describes assisted living as:

A residential setting that provides or coordinates flexible personal care services, 24-hour supervision and assistance (scheduled and unscheduled), activities, and health-related services; has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences; has an organizational mission, service programs, and a physical environment designed to maximize residents’ dignity, autonomy, privacy, and independence; and encourages family and community involvement.

Id. at 374.
Joe and Eileen live on the proceeds of the sale of their home. Joe was self-employed throughout his career, and he never started a pension fund for himself and Eileen. Statistically, they will pay an up-front fee upwards of $34,000 to enter the assisted-living facility, and their monthly rent for a one-bedroom apartment will be more than what they now pay for their two-bedroom unit. The assisted-living facility is clearly beyond their long-term means. How long will their funds last? They could live ten more years yet, but the money probably will not last that long. Once their funds are spent, they will be dependent on their sons, or eligible for Medicaid-funded nursing home care.

Contrast Joe and Eileen's situation with that of Mary, a widow, who relocated to a new state to live with her daughter's family when her health began to fail in her late sixties. Mary's daughter was the stay-at-home mother of three kids: one nineteen and off to college, one seventeen, and a little one, aged six. Mary's arrival in her home complicated her daughter's routine, but she had the financial freedom to stay with Mary and to provide the housekeeping and personal care assistance Mary required. Mary's grandchildren helped, too. Eventually, Mary was given a terminal diagnosis of cancer; her medical needs became more palliative in

4. See id. at 375 (noting that monthly median rental rates among Florida facilities surveyed in 1993 by AARP varied from $995 to $1639).
6. Id. Medicaid finances the care, at least in part, of about three-fifths of nursing home patients. Eligibility for Medicaid subsidy is determined by income and asset tests administered by state governments. Although many patients are poor enough to qualify for Medicaid when they enter a nursing home, a substantial number become poor after they are institutionalized. Persons in this latter group deplete their assets in order to meet their long-term care bills, eventually "spending down" and becoming sufficiently poor to qualify for Medicaid.
7. See Marshall B. Kapp, Enhancing Autonomy and Choice in Selecting and Directing Long-Term Care Services, 4 ELDER L.J. 55, 58-61 (1996) (personal care is assistance with activities of daily living [ADLs] such as bathing, dressing and using the bathroom or with instrumental activities of daily living [IADLs] such as housecleaning, cooking and transportation).
8. Palliative care focuses on relief of pain rather than cure of illness; it is usually administered to terminally ill patients to help ease their suffering.
nature, and she was eligible for home hospice care,\(^9\) which Medicare covered for five months until she died.\(^10\) Throughout those months, Mary’s daughter and her children continued to provide for her mother’s home and personal assistance needs.

Had Mary’s daughter and her family not been able to house and care for Mary, she first would have required part-time home care\(^11\) in her home state, where she would have been alone once her caregivers left for the day, and, later, nursing home care. Medicare and Medicaid probably would have covered most of these services.\(^12\) Though they did not think in these terms, Mary’s daughter and son-in-law saved Medicare a great deal of money. They saw the situation only in terms of keeping Mary comfortable and close to loved ones in the midst of a painful and scary illness.

Mary was fortunate to live and to die her last months as she did. Her situation is the kind most Americans would like to find themselves in at the end of life.\(^13\) Medicare could enable many more families to provide this kind of end-of-life experience to their loved ones by providing even modest remuneration to those family caregivers who perform the sort of homemaking and personal assistance services Mary’s daughter and her grandchildren did for her. Mary’s daughter was able to care for her mother because she was not tied to paid employment; her financial situation enabled her to be a caregiver. Many families do not have this financial flexibility.

Another option exists for Joe and Eileen. Their grandson and his wife own a large home with a finished basement and they would welcome Joe and Eileen to live there. They would be near their small great-grandchildren, they would have enough space and


\(^10\) See id. at 740.

\(^11\) See Kapp, supra note 7, at 59-61. “Home health care consists of medical and skilled nursing interventions such as diagnosis and treatment, nursing care, medications, physical and speech therapy, and the provision of medical supplies and equipment.” Id. at 60.

\(^12\) See id. at 60-61, indicating:

Public funding for these various services is substantial but quite restricted. The Medicaid program currently finances physician-ordered home health services and may, at a state’s option, provide an entitlement to personal care services prescribed by a physician or authorized under an approved state plan.... Medicare finances home-based services that are focused on skilled nursing and therapy rather than non-medical support services and that are less likely to be used as a form of long-term support.

\(^13\) See Nathalie D. Martin, Funding Long-Term Care: Some Risk-Spreaders Create More Risks Than They Cure, 16 J. Contemp. Health L. & Pol’y 355, 360 (2000) (citing informal survey sources suggesting these are the prevailing preferences of Americans).
autonomy to feel independent and enough family contact to get help with what they cannot do, and, in the event anything should go wrong, their grandson and his wife would be close at hand. Who would help care for them during the day, though? Their grandson works in his father's business, and their granddaughter-in-law works part-time; as it stands, she would find any suggestion that she help care for her husband's grandparents yet another imposition on her busy day of mothering, keeping house, and working.

Although her job does not pay much, and putting her little ones in day care is expensive, she enjoys the job well enough and it gets her out of the house. It would not take a lot of financial incentive to tip her mental balance in favor of staying home with Joe and Eileen, the kids, and her rambunctious new puppy. Joe and Eileen have the means to pay their grandson and granddaughter-in-law a modest rent, and that might be enough to tip the balance. If their Medicare insurance allowed for modest remuneration to a family member who provided their care, that too, might tip the balance. Medicare does not currently provide such remuneration, but perhaps it should. Other persons who are not as well-situated financially as Joe and Eileen have even greater need of such a benefit. As it stands, Joe and Eileen will be exhausting their current funds at an assisted-living facility that they do not really need and they will become dependent on Medicaid to bankroll their eventual move to a nursing home, which will be expensive.

Family care-giving of the elderly is often a woman's issue. Statistics show women are poorer and older in their declining years than men, and that women—daughters, nieces, and grand-

14. See Kapp, *supra* note 7, at 89 (claiming that "[t]he current system ... overwhelmingly works against empowerment of the family as home and community-based caregiver, both through narrow restrictions on reimbursement and state professional licensure laws...").

15. See Binstock, *supra* note 5, at 320 (noting that, in contrast to Medicaid, Medicare does not finance long-term nursing home care).

Medicare also pays for some nursing home and home care. The services covered are for post-acute or "subacute" care and not a broader range of non-medical long-term care services that are often needed by a functionally disabled older person. Following hospitalization of a few days or longer, Medicare pays for up to 100 days of care in a skilled nursing facility as long as the care includes skilled nursing and/or rehabilitation on a daily basis.

*Id.*

daughters, by blood or by marriage — are by far the most likely to
give care to an elderly loved one. Thus, as caregivers and as those
who will one day need care — women are doubly impacted by the
question of whether Medicare and Medicaid social insurance should
provide payment to family caregivers of the elderly.

Everyone eventually will be impacted by questions of how
funding for care of the elderly should be allocated. One commenta-
tor explains the growth of the elderly population over the last
century and projections for future growth:

[I]n 1900, 4 percent of the population was age sixty-five or older.
By 1977, 10.8 percent of the population was sixty-five or older.
By 1980, that figure had increased to 11 percent. Projections
are that by 2010, 12.7 percent of the population will be at least
sixty-five, and that by 2030, 18.3 percent of the population will
have reached that age.... Furthermore, the “elderly” as a group
are getting older. The percentage of elderly individuals at least
seventy-five years of age will rise from 37.7 percent of the total
elderly population as of 1977 to 42.1 percent by 2030. The
care needs of the more numerous and more elderly persons
promise to become an increasingly staggering financial and social
burden in the United States.

The argument that Medicare should contain costs by focusing
funding on home-based care rather than on nursing home care is by
no means novel. Commentators have suggested that funding home
care is one means by which Social Security costs could be better
contained; the theory is that home care can delay or even

interruptions for childbirth, childrearing, and family responsibilities ... impoverish women financially.” Id. See infra notes 49-104 and accompanying text for further discussion.

17. See id. at 556 (noting that “[t]he literature clearly indicates that, in the absence of
a spouse, the primary caregiver for the elderly parent is a daughter, daughter-in-law, or
niece”); see also Binstock, supra note 5, at 319 (asserting that “[t]he vast majority of family
caregivers are women”).

18. Martin, supra note 13, at 355-56 n.3.

19. See Binstock, supra note 5, at 317 (noting that the aging of the population is
accompanied by other factors impacting health expenditures for the elderly).

A few recent studies have focused on population aging as a factor in U.S. health
care costs. They show that the impact of aging and other demographic changes
on expenditures has been dwarfed by the combined effects of other factors such
as increases in the intensity and utilization rates of health services, health-
sector-specific price inflation, and general inflation.

Id.

20. See William G. Weissert et al., Cost Savings from Home and Community-Based
Services: Arizona’s Capitated Medicaid Long-Term Care Program, 22 J. HEALTH POL.
POLY & LAW 1329 (1997) (detailing substantial Medicaid savings achieved by promoting extensive
home and community-based care services as an alternative to institutional care); see also
eliminate the need for prolonged, more expensive nursing home care. Projected spending increases for Medicare benefits over the next generation are substantial:

In 1996, spending on Medicare was 2.4% of the GDP [gross domestic product]; by 2030 it is projected to approximately triple, to 7.1%. Between 2010 and 2030 federal spending for Medicare, as a percentage of the GDP, is projected to increase by 73% as compared to a one-third increase in the percentage of the GDP projected for OASI [Old Age and Survivors Insurance, the non-medical component of Social Security] spending in the same period.  

Observers are divided in their assessment of whether a change in the Medicare home health benefit can stem the anticipated revenue bleeding. Recent developments in the funding of kinship care of children through state foster care payment systems can be instructive for the debate over whether and how to compensate home care of the elderly. Home care covers a wide variety of services; this Note will
discuss how Medicare and Medicaid can compensate family members who provide unskilled\textsuperscript{24} home care services to their elderly relatives. This Note draws on a recent Florida state plan to compensate “kinship care” of children as a starting point from which to argue that compensated care of the elderly by their families should be a feature of the Social Security program. This Note surveys and pulls threads from related legal scholarship to present a broad policy picture of why and how we should seek to achieve this goal.

The first part of this Note gives an overview of Florida’s Relative Caregiver Program, enacted in 1998, and the 1996 Congressional mandate that precipitated its enactment. The second part examines the traditional barriers to public support of kinship caregivers of both children and the elderly through a review of recent scholarship on these topics. The third part of this Note draws parallels between the policies underlying Florida’s Relative Caregiver Program and policies that are advanced for compensating family caregivers of the elderly. The policies are explored alongside proposals that have been culled from the literature advocating compensation for family caregivers. Finally, the fourth part examines workers’ compensation case law as a model of how cash compensation for kinship care, based on specific policy objectives, can be administered and evaluated. This section also argues that the common roots of workers’ compensation and Social Security as early twentieth century social insurance weighs in favor of including kinship care compensation in the Medicare and Medicaid funding schemes.

A few significant exclusions have been necessary due to the reach and scope of the topic and should be noted. First, private medical insurance is outside the scope of this Note, which is instead concerned with public insurance in the form of Medicare and Medicaid benefits. Private long-term care insurance is touched on in passing because it can, and likely will, increasingly provide a significant source of funding for nursing home and long-term professional home care; it is, however, otherwise outside the scope of discussion. The financial reasons for compensating family caregivers with public funds have analogs in the private insurance market, but those considerations will not be addressed.

Second, for simplicity, this Note speaks almost exclusively of the elderly care recipient. The discussion is nonetheless largely applicable to the non-elderly Medicare or Medicaid recipient as

\textsuperscript{24} That is, care that does not require a skilled nursing background. See id.
well. The class of the elderly, defined as those sixty-five and older for Social Security purposes, is quite diverse. The situation of younger disabled, terminally ill, and chronically ill adults who require ongoing care will implicate many of the same policy considerations. This fact can most clearly be seen in the fourth part, which discusses workers' compensation as a related legal field. The cases discussed therein involve disabled younger adults rather than the elderly. The terminology used was chosen for the sake of semantic simplicity rather than out of any intention to marginalize the needs of other cohorts. Finally, neither discrimination against the disabled and abuse of the disabled are discussed, nor are age discrimination and elder abuse, except as they pertain to the main discussion.

**KINSHIP CARE OF CHILDREN**

Foster care exists in place of orphanages as the means by which states provide care for children who must be removed from their homes due to neglect or abuse by their parents or due to their parents' death, incarceration, or abandonment. The programs are state-run and administer both state and federal funding. Traditionally, relatives who took in a displaced child were ineligible for the state maintenance payments given to unrelated foster parents.

25. KAPP *supra* note 6, at 1-2, 3.

26. See Note, *The Policy of Penalty in Kinship Care*, 112 HARV. L. REV. 1047, 1048 (1999) (noting that "[w]hile in the past, children were placed in orphanages or asylums, today an abused or neglected child is more likely to be placed in foster care with a foster parent who receives government-funded maintenance payments").

27. See *id.* at 1050 (surveying the range of state and federal funding programs administered by state foster care programs).

28. See *id.* (explaining the traditional policy link between moral obligation and reduced financial support for relative caregivers). The author states:

States that exclude relative caregivers from state foster care use this moral obligation as a substitute for the legal obligation ("inducement") parents have to support children, and as a further substitute for the monetary support ("inducement") that states offer nonrelative foster parents. Such a view implies that aid above and beyond the TANF rate (such as foster care maintenance
As one author explains, “Although children placed in formal kinship care arrangements may receive foster care payments, children in informal kinship care are eligible to receive only TANF [Temporary Assistance to Needy Families] benefits. State funding options and incentives often force relatives into informal kinship care, which offers significantly lower reimbursement.” Program technicalities can thus function to punish relative caregivers even where the policies are facially neutral as between relative and stranger foster caregivers.

Foster care systems have been increasingly burdened in recent years due to parallel trends: increasing numbers of children removed from homes and decreasing numbers of available foster parents. While relatives have always been informally called upon to step into the breach to care for children, the financial burdens of feeding and clothing another child have become so great for some kinship caregivers that some children are being put back into the system by their overextended relatives.

As one commentator explains, the systemic bias against relatives has been changing in recent years in response to the growing pressures on foster care systems:

In 1996, the United States Congress for the first time made explicit a recognition that kinship care serves both permanence and family preservation and support goals. To be eligible for federal Title IV-E foster care maintenance funds, Congress ordered states to consider giving preference to an adult relative over a nonrelative caregiver. Still assuring the child protection goal, the 1996 amendment requires the relative to meet all relevant state child protection standards.

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The Florida state legislature in 1998 responded to this Congressional mandate by enacting the Relative Caregiver Program, which provides financial assistance to relatives within the fifth degree of relationship to a parent or stepparent of the child who are caring full-time for a child in the role of substitute parent. The child must have been abused, neglected, or abandoned, and placed with the relative under chapter 39 of the Florida's dependency statute, which expresses a preference for relative placements over placement with nonrelatives. Id. at 471. Relatives who qualify for the Relative Caregiver Program are not required to meet foster licensing standards, but a home study must be completed.

This growing legislative recognition that the extended family unit is an important part of the social fabric of a child's life gives rise to the question of whether other public programs should be modified to support the extended family unit in related contexts. For example, providing care to an elderly relative is equally burdensome as caring for a relative's child; care of any dependent relative presents similar financial hardships to the caregiver when the care giving interferes with employment, income, and other family responsibilities.

TRADITIONAL POLICY AND COMMON LAW BARRIERS TO COMPENSATING FAMILY CAREGIVERS OF CHILDREN AND THE ELDERLY

Probably the most enduring barrier to compensating family caregivers has been the implied moral duty that family members have to care for one another, particularly in times of trouble. In
reference to adults who take in related children that otherwise
would enter the foster care system, one commentator writes:

That relatives feel a sense of obligation is no doubt true. Relatives
do not always feel that they are making a choice to care for children who
are abused or abandoned by family members. Why then, ask legislators,
should the state pay relative caregivers to furnish care they would provide
anyway — especially when paying them would result in greater state
expenditures? Nonetheless, in this context, treating the extended family
differently from stranger caregivers is fraught with problems. Relative
caregivers need the same or more assistance as nonrelative caregivers.
Like unrelated foster parents, relative caregivers take on an additional
burden when they decide to care for a child. Though they are related,
their homes are not the children's homes, and therefore the cost of
care is greater. In fact, relatives without adequate financial
resources are sometimes forced to relinquish children to the foster
system.40

It is important to recognize that kinship care of abused and
neglected children is both a burden and a moral obligation in the
policy-setting process. The Florida state legislature acknowledged
this duality by authorizing its Relative Caregiver Program in 1998
to support acceptance of the moral obligation by lifting some of the
attendant burden.41 In the context of the elderly, a moral duty to provide
needed care is perceived to rest with children, nieces, and nephews,
or grandchildren of the frail elderly. Hence the guilt so many
experience when deciding to put an elderly loved one in a nursing
home: that choice is frequently perceived as a failure to fulfill a
moral obligation to the loved one. The obligation to provide care,
however, is not legally imposed.42 Parents have a common law duty
to care for minor children, but the duty does not flow both ways.
Adult children have no affirmative duty either to provide care for

40. Note, supra note 26, at 1055-56.
42. See generally Blair, supra note 36, at 767-68 (arguing that the imposition of such a
filial duty of care is socially desirable).
their parents, or to intervene to prevent negligence by another sibling or family member who is ostensibly providing care to that parent. Nevertheless, according to two advocates of tax incentives for care giving,

[the] majority of families respond voluntarily to the needs of their aged members to the best of their capabilities... "[A]t best, incentives facilitate the process and make it easier for the already committed and do little to change the minds of the refusers." In this way... incentives are seen to support existing caregiving situations, but not to change the behaviour of families who at the outset reject their caregiving role.

Thus, the perceived moral duty is common to kinship care of both the old and the young. The attendant burdens are also common to the two situations.

Some commentators go as far as to suggest the law should impose a duty on children to care for their elderly parents with the goal of enabling prosecution of those who abuse or neglect their dependent elders. In the same way the federal government provides a safety net (basically, through TANF, food stamps, and other welfare programs) to enable poor parents to fulfill their legal duty to care for their children, the government could extend a cash benefit to poor adult children who are willing to give care and are under a duty to do so but cannot because of financial limitations. The logic is reflexive:

Some of the same reasons underlying filial responsibility laws, which place a duty on adult children to provide financial support to indigent parents, are applicable to the question of whether children should face criminal liability for neglect of an elder. The idea of reciprocity serves as a leading justification for imposing a legal duty. The reciprocity concept rests upon a moral ground. Parents owe a duty to provide care and support for their children; therefore, children should owe a corresponding duty to care for their parents. A strong cultural tradition supplies another reason for imposing a legal duty.

43. See id. at 768 (noting that criminal liability "for a failure to act ... such as failing to care for an elderly parent" requires "a corresponding legal duty to act;" where no such duty exists, omissions are not criminal).
45. Blair, supra note 36, at 780.
In spite of the philosophically compelling argument for duty based in reciprocity, practical political barriers exist to enacting such standards. Employers, for example, perceive that legally imposed family duties would interfere with work performance:

One argument against imposing such a duty points to the burden this duty would place on the adult child. For instance, one corporation conducted a survey of some of its employees and found that those who cared for elderly relatives or friends reported their caregiver role interfered with their home and work responsibilities. The survey also found a decline in productivity and a greater incidence of absenteeism and tardiness among caregiver-employees as compared with other employees.46

The power of employers as an adverse lobby, combined with the intangible potential benefits of a filial duty law, do not bode well for any such proposal.

Insofar as the absence of a legal duty has been used to justify full foster care support payments for relatives who give care to children out of a sense of moral obligation, by analogy, the case for payments to relatives who give care to their elderly is stronger absent a legal duty. That is, because kinship caregivers are finally being seen as more like strangers who have no legal duty to give care than like parents, who do have a legal duty to provide care, they are receiving more support.47

In addition to acknowledging the burdens associated with foster care giving by relatives, the passage of Florida's Relative Caregiver Program also served to address a trend that is common among the states:

In the past ten years, child welfare systems have increasingly come to depend on the placement of dependent children with relatives because of the inability of the public systems to absorb the numbers of children needing care outside the home of their birth parents. This toll on the child welfare system comes both from a shrinking supply of foster homes and an escalating demand for out-of-home care.48

46. Id.
47. See Note, supra note 26, at 1054-55 (outlining the competing theories of inducement and moral obligation in the foster care setting, as discussed supra notes 36-40).
The Relative Caregiver Program addressed both the burdens attending the moral duty motivating family members who take in displaced children and the need to increase the pool of caregivers for neglected and abused children.

**Policy Reasons for Compensating Caregivers of the Elderly**

In addition to the Relative Caregiver Program, the 1998 Florida legislature also enacted legislation authorizing privatization of parts of the foster care system.\(^{49}\) In so doing, its stated goal was to better protect foster children by opening the foster care system to tort liability through private legal actions.\(^{50}\) The value of extended families is mentioned throughout the introductory paragraphs of the Relative Caregiver Program provisions.\(^{51}\) The widely appealing social goals of protecting the rights of children, and of making policy reflect social dynamics, appear to have played a large part in the enactment of these new code sections.

The potential for fulfilling appealing social goals by subsidizing family caregivers in the context of the elderly is equally great. Most elderly folks still retain their legal rights of self-determination and some maintain a measure of personal wealth. By potentially increasing her care options, family caregiver compensation can allow an elderly woman, for example, a still greater degree of self-determination and control over her care as she grows older. Other worthy goals, including saving Social Security funds, recognizing and rewarding the societal contributions of caregivers, and strengthening the family unit, can also be promoted by this means.

This section will evaluate the various caregiver compensation proposals in the literature against the social goals they each purport to further. Among the compensation proposals examined are pension credits, direct cash remuneration, tax benefits, and family leave policies that allow for employment flexibility when an elder requires long-term care.\(^{52}\)

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50. Id.
52. By necessity, some related and intriguing proposals have been left out of the survey. For a discussion of the importance of funding adult day care, see generally Meuser, supra note 20, arguing that "governments and employers can and should support adult day care programs because they are inexpensive, successful, and a desired community based alternative to institutional long-term care." Id. at 224. For a discussion of contract law issues, see generally Henes, supra note 39, demonstrating that the family rule in contracts is anachronistic and should be abandoned, thus allowing family members to enforce contracts
Increasing the Autonomy of the Elderly

Foremost among public policy and reform goals in this area should be to protect the fragile autonomy of the aging and ill. As one advocate for the elderly writes:

Legal restrictions on family caregiver payment ought to be eliminated in any expanded home and community-based LTC [long-term care] system. Removing such restrictions would encourage and enable more family caregiving. This development, in turn, would enhance client choice and control by providing many clients with a broader range of options about the who element of their care; it is assumed that a substantial percentage of clients would prefer family caregiving as a substitute for or supplement to care provided entirely by strangers. Besides being preferred by many clients, family caregiving will also frequently be of higher quality, because family members have a stronger personal ethical commitment and personal attachment to the client’s well-being than even the most conscientious professionals.53

In addition to emphasizing the importance of autonomy on this macro level, Marshall Kapp also advocates enhancing elder autonomy on the micro level; that is, the day-to-day decisions about organizing a home care schedule:

For the home care client, control concerning the routine and minutia of care may be central. For instance, what time will the personal assistant arrive? What food will be brought into the home, how will it be prepared, and when will it be served? When will the client get dressed, and with what attire? ... Most important, how will the personal assistant be located, hired, and fired?54

When the home care assistant can be a person with whom the “client” is comfortable and familiar, and with whom he shares an understanding of how household tasks are organized, the potential for conflict and stress is reduced.55 Kapp suggests a model under

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53. Kapp, supra note 7, at 90 (footnotes omitted).
54. Id. at 64.
55. See id. at 63 (emphasizing that “perception of personal control plays a critical role in an individual’s long-term physical and emotional health and well-being”). “Enhanced client autonomy is associated with the practical benefits of fostering independence over time, [and]
which the elderly “clients” of home care are given control over the hiring assets in their coverage: “[G]ranting clients the purchasing clout to hire, fire, and determine wage increases would provide them with their choice of personal attendants... and support family members and other informal caregivers who are presently ineligible for third-party payments.”

Family caregivers could benefit under this model, but only at the discretion of the elder.

Marshall Kapp identifies both financial and legal pressures on would-be family caregivers as the chief barriers to the inherently preferable family home care model. He finds that questions of legal status constitute a significant part of these pressures:

In most home settings, families provide the bulk of direct hands-on personal and homemaker services for disabled individuals. Empowering the client in reality often means empowering his or her family support system.... A fundamental goal of public policy should be encouragement of family caregiving, as a supplement to or substitute for formal [long term care] services. The current system, however, overwhelmingly works against empowerment of the family as home and community-based caregiver, both through narrow restrictions on reimbursement and state professional licensure laws that place family members in legal purgatory for engaging in certain beneficial activities.

Not only do these barriers prevent willing family members from engaging in long-term caregiving, but they also contribute to the frustration experienced by those who do provide care. Kapp provides a fairly extensive discussion of professional licensure restrictions. That material is outside the scope of this Note, other than to explain in brief that they require the hiring of a trained medical worker to perform certain medical tasks, such as administering medication and shots. His home care proposal includes lifting such restrictions in the narrow circumstance of a

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56. Id. at 64.
57. Kapp would counterbalance this support of the family unit with increases in the “capacity of local Adult Protective Services agencies to receive, investigate, and respond to reports of abuse and neglect taking place by family caregivers in the client’s home” to ensure the elder’s safety. Id. at 92.
58. Id. at 89. These activities include administering prescription medications and operating certain medical equipment. Id. at 91.
59. Id. at 91.
family caregiver who executes directions given by her elder's doctor.\textsuperscript{60}

Kapp's analysis does not ignore the very real possibility of abuse of elders by family members who have taken on the responsibility of providing care. He proposes that "public policy should begin with a strong presumption in favor of client/family empowerment, leaving open access to formal mechanisms for disempowering the family upon proof of client wishes or family misconduct dictating otherwise."\textsuperscript{61} With appropriate monitoring, the benefits of a system that empowers the elderly and their families can outweigh the ever-present risk that someone will abuse the system.\textsuperscript{62}

\textit{Savings to Social Security}

In furtherance of the current national concern with shoring up Social Security, compensating family members who care for their elders at home could help cut the significant expenditures made by Medicaid for full-time, long-term nursing home care.\textsuperscript{63} Nursing home care is the most expensive form of long-term care.\textsuperscript{64} A dedicated family care provider often can help an elderly Medicare or Medicaid recipient avoid nursing home care, and therefore can result in a savings to the system. As one critical commentator writes:

Medicare provides third-party payment for the hospitalization costs of those sixty-five and older largely out of tax revenues in the form, for most workers, of payroll withholdings.... The generosity of the payments available for hospitalization, their warrant of indefinite self-renewal, and the relative ease of obtaining them — qualification is satisfied by the receipt of any service in a hospital — contrast with the relative difficulty of qualifying for home health care and the lack of any subsidy whatsoever for care of a mainly custodial kind. This bias favors expensive, hospital-based treatment over less expensive, home-based care. In effect, Medicare creates three classes of health-

\textsuperscript{60} Id.
\textsuperscript{61} Id. at 89.
\textsuperscript{62} Id. at 92.
\textsuperscript{63} See Meuser, supra note 20, at 221 n.9 (citing statistics that the annual cost of nursing home care per person is $40,000).
\textsuperscript{64} See id.
related dependents among the elderly, only one of which — the most costly — is thoroughly subsidized. 65

Home care by a family member falls into the category of mainly custodial care. Much of family care involves homemaker services which require no medical training: cooking, cleaning, shopping, entertaining, dressing, bathing, and providing companionship and supervision for an elder who is frail, or prone to wandering, or to medical crises. 66 Though this work is physically demanding and time-consuming, Medicare pays for these services only when received in conjunction with qualifying nursing services in the home, or in a full-time nursing facility on a short-term basis. 67 In a policy irony, some elderly persons end up in full-time nursing facilities not because they require full-time nursing, but because they require full-time personal assistance services that could be provided in the home or the community. 68 If Social Security allowed compensation for these services by a family member, many elderly persons could remain at home with, or in the homes of, family members who would be willing to provide the services needed.

Under current Medicare and Medicaid rules, only a licensed professional can provide even nonmedical services and receive payment for doing so. One critic of the current Medicare home health benefit writes:


66. See Kapp, supra note 7, at 60 (describing the scope of personal assistance and homemaker services).

67. See Davis, supra note 20, at 224-26 (listing the requirements for participation by a home health agency in the Medicare home health benefit; the patient in question must be "confined to his home," he or she must be under a plan of care designed and overseen by a physician, the physician has to be qualified to sign a certification statement and plan of care, and the patient must require skilled services, such as nursing care).

68. See Martin, supra note 13, at 356 n.6 ("Medicare only covers a small portion of all nursing home stays in the United States, because Medicare and the gap policies that supplement it only cover short-term post-acute care for persons discharged from a hospital who need skilled nursing care.").

69. See Meuser, supra note 20, at 239-41. Meuser's discussion of the Illinois experience illustrates this dynamic:

Illinois' Choices for Care Program ... provides anyone entering a nursing home after July 1, 1996 a free consultation with a professionally trained case manager. Some case coordination units in Illinois have already reported that as many as 8% of persons who used the case managers have requested community-based care over nursing home care.

Id. at 240.
Another glaring problem with the current structure is the amount and frequency of nonmedical services provided. Recall that home health aid services, though perhaps containing no medical basis, are reimbursable expenses if coupled with otherwise reimbursable nursing services. This structure creates a system of federally funded companionship.70

Services that can as easily be provided by family members cannot be compensated even at a minimum wage rate, while the much higher wages earned by a home health aid are remitted legally.

A Case Study in Chicago

Patrick Murphy, Public Guardian of Cook County, Illinois, discussed the cost savings to Chicago localities of keeping elderly wards in the community in a law review essay.71 Besides acting as advocate and guardian ad litem for children, his office also acts as guardian for those elderly persons who are incapable of caring for themselves or their estates and whose families cannot fill the guardianship role.72 While their context is somewhat different, the mechanics of their living in the community can be instructive in the Social Security context.

Patrick Murphy began moving his wards out of nursing homes early in his tenure when, upon visiting wards living in nursing homes, he began to realize many of them did not need to live there. He has come to understand that:

Too many elderly men and women spend their last days, months, and even years in nursing homes, not because they need it, but because it is the only placement available for the money, usually public money. Our public laws encourage institutional care for the elderly. Taxpayers fork over three thousand dollars a month or more to nursing home operators to care for ma, pa, and Aunt Tilly.73

Patrick Murphy’s office began to move folks out of nursing homes and to place two or three persons together in apartments or homes with round-the-clock housekeepers — something none of the wards

70. Davis, supra note 20, at 238. The proposal made in this article would lessen the occurrence of this phenomenon by making homemaker services reimbursable to family members at rates far below nursing charges.
72. Id.
73. Id. at 502.
could afford individually, but could easily afford with their pooled resources.\textsuperscript{74}

Not only does this approach result in significant savings — Patrick Murphy told a judge he could care for a ward for two-thirds the cost of full-time nursing home care\textsuperscript{75} — but it also results in better socialization for some of his isolated and withdrawn wards,\textsuperscript{76} and allows some to keep their homes when they otherwise are financially unable to maintain the home. Murphy's office will, upon deciding that a home is salvageable, make necessary repairs and place other wards with the homeowner as boarders. Their estates pay rent to the homeowner's estate, and taxes and insurance can be paid by the homeowner's estate out of the rent money.\textsuperscript{77} The care given by the housekeepers is personal, non-confining, healthier psychologically and socially, and financially more empowering for these vulnerable wards of the county.

The experience of Patrick Murphy in Chicago could be replicated on a nationwide scale if Medicare and Medicaid would permit compensation for family caregivers. In Patrick Murphy's situation, families are either not available or have been cut out of the picture by courts because they have neglected, abused, or exploited their elders.\textsuperscript{78} However, where families are willing and available, providing them with compensation may be the enabling factor that permits them to keep their elders at home rather than sending them to nursing facilities when such a move would be unnecessary from a medical standpoint.\textsuperscript{79}

\textit{A Feminist Ideal: Rewarding Caregiving Work and Stopping the Cycle of Poverty for Women}

Feminists long have emphasized the lack of compensation for women who raise children as evidence of patriarchal dominance and the triumph of male market work values over female values of care and work for home and family.\textsuperscript{80} Besides the troubling philosophical inequities identified by this critique, some significant social

\textsuperscript{74.} Id.
\textsuperscript{75.} Id. at 504.
\textsuperscript{76.} Id. at 503.
\textsuperscript{77.} Id.
\textsuperscript{78.} Id. at 501.
\textsuperscript{79.} See Cohen, supra note 65, at 2238-39.
\textsuperscript{80.} See Korzec, supra note 16, at 549 (introducing the feminist ethic of care and the work of Carol Gilligan, which emphasizes "solidarity, empathy, and community responsibility," as a counterpoint to the traditional approach of law and its focus on "autonomy, personal responsibility, rationality, and individualism").
insurance costs may arise from it as well. One commentator describes the long-term implications of women who focus on uncompensated care giving work to the exclusion of paid market work as follows:

[W]omen who perform the traditional role of wife, without ever entering the paid workplace, risk impoverishment from divorce or widowhood. Almost eighty percent of women who are poor as widows were not poor before their husbands' deaths. Ultimately, the hardships created by this widening gender income gap results in "an increased demand for transfer payments and public support."81

Thus, a woman who focuses on care giving to the exclusion of employment, during all or even part of her adult life, must be aware that insofar as she relies on her spouse's income, she may be endangering her future financial security.82 Not only do women tend statistically to outlive their husbands83 and their husbands' pensions,84 but also, any absences they take from employment adversely impact their own pension earnings:

[M]easured in traditional terms, women lag behind men in professional advancement. The current literature on the achievements of women lawyers is instructive.... [A]t all levels women lawyers earn less than their male counterparts.... Women's economic disadvantages translate to lesser lifetime earnings and smaller pensions. These economic facts help explain the growing poverty suffered by elderly women, including the frail elderly. Ultimately, women's work inter-ruptions for childbirth, childrearing, and family responsibilities result from the gendered nature of family roles in American family life. Clearly, these gendered family roles impoverish women

81. Id. at 560.
82. See id. at 559 ("Basically, the long-term economic effects of placing family responsibilities first lead to the impoverishment of single, divorced, and elderly women.").
83. See GEORGIA M. BARROW, AGING, THE INDIVIDUAL, AND SOCIETY 313 (6th ed. 1996) ("Widows constitute nearly one-half of all women 65 and over. Of women 65 and older who live alone, 85% are widows.").
84. See id. at 313, noting that
Some widowed women depended on their husbands' incomes, and when retired, on their husbands' private pension plan or Social Security. More often than not, private pension plans fall sharply when a retired spouse dies. The death of a spouse also lowers the amount of Social Security benefits.... Data from a national sample of widows of all ages found that widowhood decreased living standards by 18 percent and pushed into poverty 10 percent of women whose prewidowhood incomes were above the poverty line.

Id.
financially. More fundamentally, they may psychologically and socially impoverish both men and women by discouraging the creation of balanced personal and professional lives.  

One of the reasons elderly women tend to be poorer than their male counterparts is that their pension benefits, if any, have been decreased by years taken off from employment in the market to raise children or otherwise address family needs.

An elderly woman's needs, in turn, may require that her daughter take time out from the workforce to give her care, perpetuating the cycle of these dynamics, causing the daughter to lose benefits over time. In addition, the daughter has lost opportunity costs to consider, as well:

Although families provide a tremendous volume of in-home care to their disabled relatives, such caregiving often exacts a heavy personal, physical, and emotional toll. Not incidentally, there is frequently a substantial financial burden, in terms of lost opportunity costs.... Yet current Medicaid regulations as well as most states laws (with several notable but limit exceptions) prohibit the payment of public monies to family caregivers. Ironically, the simple fact of a blood or marriage relationship generally disqualifies a person as a paid caregiver who otherwise could be chosen by the client and financially compensated for services performed.... These restrictions force relatives to enter or remain in outside paid employment rather than to provide home care to the client....

In addition to lost wages, lost pension benefits, and lost opportunity costs, a woman who chooses to give care to an elderly loved one will incur the immense emotional burdens of that undertaking:

Generally, one adult child becomes the "primary caregiver" of the elderly parent.... The literature clearly indicates that, in the absence of a spouse, the primary caregiver for the elderly parent is a daughter, daughter-in-law, or niece. As a result, when contemporary writers bemoan the pressures on the "sandwich

86. See id. at 555 n.66 (citing census statistic that "women comprise just under 60% of senior citizens over 65, but 75% of the poor elderly").
87. See id. at 553 (noting that this is in juxtaposition to "the model of the average ideal worker: a decidedly male norm. This ideal worker essentially devotes all his time to career advancement; his wife subsidizes his efforts by providing homemaking and childrearing services. Moreover, this ideal worker ... toils full-time without interruptions for childbirth, childrearing, or caretaking of elderly parents.").
88. Kapp, supra note 7, at 89-90.
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89. Korzec, supra note 16, at 556.
90. See Keefe & Fancey, supra note 44, at 199-200 (discussing caregiver pension credit programs in Norway and Britain).
91. See generally id. (analyzing the range of public benefit programs available to family caregivers in Canada and elsewhere).
92. Id. at 203.
93. Id.
do not have the financial resources to purchase services or adequate supplies and/or equipment during the taxation year, or if they are unable to meet the maximum care expenses required to be eligible for a tax credit. Those tax credits that are non-refundable also have limited use for those families who have no tax liability.  

These limitations of the tax benefit approach make it a less desirable means of compensating caregivers than other approaches. Pension benefit plans credit work time to caregivers for purposes of calculating long-range social insurance benefits; Keefe and Fancey discuss public pension benefit plans in Norway and in Britain for caregivers. In this country, such a plan could award Social Security employment credits for time spent caring for relatives. In other words, the caregiver’s Social Security records would reflect she was employed for the period during which she was giving care, thus allowing her to maximize her Social Security benefits at retirement. This award would allow a worker to be free from pension penalty when she needs to make time in her life to care for a loved one. Keefe and Fancey also note:

The intention of this benefit is to protect caregivers who cannot seek employment because of caregiving responsibilities against income losses from future retirement benefits.... In some countries... pension credits are maintained [privately] for employees who must leave their jobs to give care to relatives for temporary periods. These benefits are a substitute for lost pension benefits through employment.

This compensation system is creative and admirable based on its forward-looking approach, but it gives no assistance to the caregiver at the time she is giving care. Alone, this system does nothing to lift the barriers to care giving for those who cannot afford to be income-free while caring for a loved one for weeks, months, or years.

In this way, pension benefits are similar to the Family and Medical Leave Act (FMLA), which protects a worker’s job when she takes leave because of a personal medical condition or because

94. Id. at 201-02.
95. Id. at 199-200.
96. Id. at 200.
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of the needs of a child, spouse, or parent. 99 The FMLA does nothing to ensure continued income while the worker is on leave; the extent to which the worker's terms of employment allow for paid vacation determines whether she continues to receive her pay while on leave. While the FMLA's guarantee of job security is invaluable and groundbreaking, it may not offer enough protection for every worker. 100

Supporting the Family Unit

Both the Florida Relative Caregiver Program and proposals for elder caregiver compensation seek to support the extended family unit and seek to provide continuity, comfort, and predictability for children and elders. Seen from this perspective, the goal of supporting the family unit closely parallels Marshall Kapp's goal of promoting elder autonomy and self-determination, as discussed earlier. "[F]amily preservation and support, also appears to be enhanced through relative care giving. Historically, both in this country and around the world, extended families have served as a resource during times of family distress."101

Additionally, supporting the family unit in this way may help accomplish the goal of preventing some elder abuse. The theory is that, by lifting some of the financial pressures inherent in care giving, caregiver compensation can operate to help defuse a potentially abusive situation:

placement. The basic leave provided by the FMLA is twelve work-weeks of leave in a leave calculation year. Employees will be eligible for FMLA leave if they have been employed twelve months and have worked at least 1250 hours in the twelve months prior to the leave.

Id. 99. See id. (noting that "[t]he FMLA does not protect an employee who needs time away from work to care for a family members who is not covered by FMLA. For example, an employee may not use FMLA leave to care for a parent-in-law, sibling, grandparent, or grandchild.").

100. See Korzec, supra note 16, at 556-57. Korzec critiques FMLA as follows:
The Family and Medical Leave Act of 1993 fails adequately to address the many problems facing the 'sandwich generation' of middle-aged women responsible for caretaking their own children as well as the elderly parents.... To date, the practical effect of the Act has been felt more in the area of maternity leave than in the caregiving of elderly parents. Since the Act provides only twelve weeks of leave, it cannot meet the long-term needs of elderly parents and their adult children.

Id. 101. Zawisza, supra note 32, at 459.
Numerous reasons for the abuse of the elderly exist. Authorities cite the economic, physical, and emotional strains associated with taking care of the elderly as the main reasons abuse occurs. Lack of financial resources and poor timing may cause abuse as well, because often the adult children who care for an elder are themselves approaching retirement or have already committed funds to their children’s college tuition or wedding expenses.¹⁰²

By lessening the financial drain on a caregiver and her immediate family’s resources,¹⁰³ proposals that seek to enable family unit care giving through financial support can render less stressful the financial elements of care giving. Just as tensions over money are understood to underlie many divorces, so too can tensions over money exacerbate latent tendencies to abuse loved ones — particularly vulnerable loved ones.¹⁰⁴

**THE WORKERS’ COMPENSATION APPROACH AS A MODEL FOR CAREGIVER REMUNERATION**

Workers’ compensation insurance is an important area in which some states have awarded cash compensation for time and labor of spouses and other family members who provide personal care. In *Close v. Superior Excavating Co.*,¹⁰⁵ the Supreme Court of Vermont upheld an order of the state’s Unemployment Commission requiring the employer to pay $207,312.40 to the injured worker’s spouse, who provided him with round-the-clock care for two years

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¹⁰³. *See id.* at 767-68 (listing lack of financial resources as a potential contributing cause of elder abuse); *see also* Vicki Gottlich, *Beyond Granny Bashing: Elder Abuse in the 1990s*, 28 CLEARINGHOUSE REV. 371, 372 (1994).
¹⁰⁴. *See Gottlich, supra* note 103, at 372.
before his condition necessitated placing him in a nursing home. The situation was extreme because the worker had suffered a head injury that rendered him prone to seizures, memory loss, and complete mental blackouts during which he would wander away from home. He required both his wife’s constant supervision and her emergency intervention during his seizures. His physician specifically gave Mrs. Close responsibility for administering her husband’s scheduled medications because his memory was so badly impaired.

The claim presented a question of first impression in Vermont, so the court looked to practices of other states for persuasive authority. It noted “[a] number of other states... have recognized spousal care as compensable when the services provided go beyond ordinary household duties.” The court went on to find that other states had adopted a flexible approach to analyzing such claims, “considering such factors as: the nature of the services provided, the need for continuous care, the employer’s knowledge of the nature of the injury and the medical condition of the claimant, and whether a reasonable value may be assigned to the services provided.” The court in Close approved the flexible approach used by the commission to evaluate the claim and declined to require the commission to use a rigid test in such cases. The wife’s services were compensated at the rate of the average minimum wage in force during the period in question.

Other states refuse altogether to award spouses compensation, and some impose more restrictive criteria for an award of compensation. The Commonwealth Court of Pennsylvania in Petrilla v. Workmen’s Compensation Appeal Board held a claim for spousal care compensation invalid based on precedent. The spouse in Petrilla provided personal care services to her husband and assisted him with the rehabilitative activities assigned by his doctor. The spouse had undergone home nursing care training before taking her husband home, but she was not a “duly licensed practitioner of the healing arts” for purposes of the Pennsylvania Workers’ Compensation Act. The Act allowed nursing care compensation only for those non-licensed persons who gave care under the supervision of a practitioner; unlike Mrs. Close, Mrs. Petrilla did not act on instructions from her husband’s doctor and could not qualify for compensation on that basis.

106. Id. at 731.
107. Id.
That states are able to adjudicate when family caregiver awards are reasonable suggests that family caregiver compensation can be a workable model in other contexts and demonstrates factors that can be appropriate to its analysis. Though employer knowledge is irrelevant for Social Security purposes, the other factors listed by the court in Close — whether the patient requires constant care, the nature of the services provided, whether such services should be compensable as a policy matter, and whether a value can be assigned to the service — can be applied in the Social Security context. Alternatively, a schedule of fees for care giving services could be enacted so that cumbersome case-by-case decision making would be required in fewer cases.

Programs in Norway, Finland, and Great Britain provide both cash compensation and pension credits to relative caregivers. In Britain, the caregiver cash benefit is the Invalid Care Allowance (ICA), individuals receiving the ICA are also eligible for pension credit in return for their care giving. Under this system, caregivers both receive current compensation and protect their future pension benefits.

In this country, workers’ compensation and Social Security have common roots in 1930s-era social insurance programs. Social Security developed at a time when the states were enacting workers’ compensation statutes to protect workers dependent on industrial wage earnings from catastrophic loss of income due to work-related injuries. The Social Security Act became law under President Franklin D. Roosevelt on August 4, 1935. It provided, among other things, for the payment of pensions to retirees. The Medicare and Medicaid programs were enacted later, as part of President Lyndon Johnson’s Great Society program in 1965. These dual developments in the United States followed an international trend toward social insurance.

Though unique, the goals of workers compensation, to make employers liable for workers’ injuries arising from accidents that

110. See Close, 693 A.2d at 730.
112. Id.
113. Id.
115. Id. at 26.
116. Id.
117. Id.
118. KAPP, supra note 6, at 64.
119. SCHIEBER & SHOVEN, supra note 114, at 18.
occur in the course of employment, can still operate to inform innovations in its sister social insurance program. Workers compensation provides a valuable example of family caregiver compensation analysis that can work in a broader context.

CONCLUSION

As Congress and states such as Florida move to recognize the importance of the extended family to young people in need of care, policymakers should carefully consider how the lessons learned from foster care should inform policy decisions about care for the elderly. The aging of the Baby Boomers and the uncertainties about the future solvency of the Social Security system make now the best time to examine how Medicare and Medicaid can better operate to support the extended family unit and the decisional autonomy of the elderly. Lifting financial barriers to care giving can relieve not only the overtaxed family unit, but also the overtaxed Social Security system. Whether through tax benefits, pension credits, cash compensation or more accommodating family leave legislation, the needs of caregivers and care recipients can and should be met more effectively in this nation's social insurance programs.

The foster care crisis has opened the eyes of policymakers to the counterproductive effects of our traditional assumptions about the mutually exclusive character of moral duties and legal incentives; that new vision should help policymakers and advocates to see how other cohorts can benefit from innovation. Effective policy innovations for older Americans will make Mary's story a reality to many more ill and elderly Americans; the Joes and Eileen's of this country need no longer be forced into cycles that strip them prematurely of their autonomy. They and their contemporaries can be well cared for and empowered to age gracefully.

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120. See, e.g., Builders Exch., Inc. v. Workmen's Comp. Appeal Bd., 439 A.2d 215 (Pa. 1982) (stating that workers compensation should be applied liberally to achieve its remedial objectives).