Center for American Progress

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An Ethical Framework for Caregiving

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Introduction

Thanks in part to a century of progress in public health and medicine, many people are enjoying healthier lives. Yet the success of modern medicine also presents us with challenges: As Americans live longer, the need for long-term care and long-term caregivers will continue to grow. Indeed, a defining issue for current and coming generations is how the United States and other nations will address the needs of their aging populations and provide adequate care for the dependent elderly.

The number of Americans over the age of 75 will more than double and the number of those over 85 will roughly quadruple in the first half of this century, overwhelming the nation's long-term care services with 80 million elderly by 2050—up from the 34 million today who are already mostly underserved or worse. The current health care system is poorly suited to serve the needs of the elderly and their families, and we lack a framework to address and improve it.

Assisted living facilities, residential care facilities, and adult day care centers are plagued by insufficient funding; shortages of staff, particularly experienced staff; and unsafe conditions. And paid caregivers account for only 20 percent of long-term care.

The majority of long-term care—a staggering 80 percent—is provided by unpaid caregivers, usually family and friends. At least six out of 10 of these caregivers are also employed in the paid workforce, and 42 percent are over the age of 50 themselves. Yet few employers have written policies regarding elder care, and even fewer subsidize any elder care benefits.

The United States is ill-equipped to handle the current demand for long-term care, and the growing elderly population will only exacerbate these strains. It is therefore vital to explore the range of concerns raised by the current system of caregiving now and create an ethical framework for addressing the issues.

A strong ethical framework for discussing and understanding long-term care—as well as evaluating programs and practices—will provide a foundation for meeting the needs of the dependent elderly and their caregivers, and serve as a guide for policymaking.

This report outlines seven ethical principles of caregiving that can help guide policy makers and other stakeholders in their efforts to ensure that the country meets its obligations to the dependent elderly *and* their caregivers. From this principled foundation, we can better envision and design specific policy strategies. The seven principles are:

- **An Ecological Ethic:** Recognizing the interconnectedness of people, systems, and policies.
- **Respect for Human Dignity:** Respecting the unique worth of all people and their pursuit of a good life at all stages.
- **Beneficence:** Maximizing benefits, including health and security.
- **Compassion:** Demonstrating concern for the well-being of others, especially the vulnerable.
- **Reciprocity:** Appreciating and compensating those who give back to society.
- **Temperance:** Taking a long view rather than looking for short-term fixes.
- **Social Justice:** Treating all people fairly and equally and building just social institutions.

This report reviews the circumstances facing the dependent elderly and their paid and unpaid caregivers. It highlights how the needs of dependent elders and those who care for them are intertwined. And it shows that policy sectors are interconnected, affecting decisions made across the policy spectrum and, in turn, affecting the lives of these givers and recipients of care. The report follows this ecological analysis and elaborates on the ethical framework that can guide policymakers and other stakeholders in their efforts to envision and implement specific, integrated policy strategies and ensure that the country meets its moral obligations to the elderly and their caregivers while also growing stronger socially and economically.

Caring About Long-Term Care

Toward Effective and Ethical Caregiving: Progressive Principles and Policies

An ethical framework for policy is necessary to stimulate discussion and provide a foundation for recognizing and meeting the needs of the dependent elderly and their caregivers. The values and principles described here are intended to guide policymaking and implementation by articulating the standards by which policies, programs, and practices should be evaluated. The United Hospital Fund recently put forth "An Ethical Framework for New York State Policy Concerning Family Caregivers," wherein they listed respect for persons, beneficence, and justice as key values.[1] These three principles have long been recognized within the field of bioethics as sources of guidance in matters of research and clinical practice.[2] And they can play a central role in policy as well.

The set of principles offered in this report—seven in all—builds upon these foundations and expands them to highlight particular ethical concerns that arise around caregiving.

An Ecological Ethic

An ecological perspective is essential for understanding the landscape of caregiving and the experience of the elderly and their caregivers. It calls for seeing caregivers and the elderly as interdependent and highly affected by national policies on the economy, health care, labor, and even immigration—policy choices that have global dimensions.

An ecological ethic shows us that the needs of family caregivers and paid caregivers are just as intricately linked as the needs and concerns of caregivers and the dependent elderly. It also shows us that our needs are tied to families in the Philippines, the Caribbean, India, and elsewhere. Health systems around the world are increasingly connected, and when we take the long view and examine patterns, it is apparent that policies from diverse sectors can work together to threaten or aid the well-being of people, and indeed entire populations, over time.

An ecologically-minded analysis reveals that caregiving is organized in a way that leads to inadequate care for some elderly, little or none for others, and seriously threatens the well-being of caregivers. The most effective policy strategies will therefore be integrated, addressing caregiving in a way that strengthens now-fragile systems, promotes sustainability, and furthers progressive values across labor policy, the health care system, immigration policy, and international alliances.

Respect for Human Dignity

Respect for human dignity is at the core of progressive values for caregiving. This principle, sometimes described as respect for persons, encompasses such values as privacy and respect for autonomy, or people's ability to make free and informed choices. Above all, it calls for promoting the ability of individuals—of all ages, abilities, genders, income levels, nationalities, races, and ethnicities—to achieve a sense of their unique worth and pursue their vision of a good life at all stages.

Respect for human dignity also raises clear systematic issues. The current care system is often too complicated for the elderly—and even their families—to navigate themselves. It fails to recognize that most elderly persons want to be as independent as possible, and their families want to be able to help make coherent care decisions with as much information and ease as possible. Lack of adequate staffing and compensation often leave health care workers understaffed, highly stressed, and unable to help families work through the system, which diminishes both their own dignity and that of families. Given caregiving's lack of social standing, caregivers don't feel respected and are often pressured to make choices that are at odds with their own well-being.

Policies that reflect a concern for human dignity could work to ensure high-quality information and options for the elderly and families with a wide variety of needs. They would also take steps to mend the health care system to allow for more coordinated, integrated care. All people should have affordable health care coverage, including those who are working as caregivers outside the paid labor force.

Policy reforms can be shaped to promote respect for people's ability to pursue their goals and to strengthen their knowledge and skills.

Beneficence

Beneficence calls for promoting and maximizing benefits—in this case primarily health and social and economic well-being—for the elderly and their caregivers. It also suggests that we should consider the ways in which the elderly and their caregivers are harmed by existing and absent policies and practices and strive to address them.

Beneficence highlights the physical, emotional, and financial strain that long-term care often puts on the elderly and their caregivers. Inadequate care for the elderly, the strain of managing a full-time job and full-time care for unpaid caregivers, and the lack of training and support for paid caregivers often causes a heavy load of financial hardship, stress, and illness.

Beneficence therefore supports designing policies that help to ensure the social, financial, physical, and psychological safety of the elderly and their caregivers wherever they reside. This means investing in attracting and retaining high-quality caregivers, developing sufficient employee leave policies, providing adequate resources for caregivers, and giving the elderly the best care to meet their needs.

Compassion

Compassion, or genuine care and concern for the well-being of others with particular attention to the plight of vulnerable people, can also help tailor

policies that will best meet the diverse needs of the elderly and their caregivers. When people are vulnerable due to their age, health status, income level, or work conditions, compassion compels us to address the root causes and ensure that people are treated with care and concern.

Compassion can highlight the often substandard care that the elderly receive, the lower standing of health care workers in geriatric care, and the dearth of corporate policies to help those providing long-term care to a family member.

Policy changes can help to create conditions that allow caregivers to treat the elderly and caregivers with the compassion that they deserve. The government can, for example, promote fair leave and labor practices to support family and paid caregivers, as well as help strengthen the health care industry's ability to provide adequate staffing and provide quality care.

Reciprocity

Reciprocity holds that those who give to society as workers, parents, and caregivers, should be appreciated and somehow compensated for their contributions.

The elderly have put in years of service and therefore deserve to be taken care of in their last years of life. And those that serve the dependent elderly—whether they are taking traditionally less-valued jobs in long-term care or whether they are contributing to the over $300 billion given each year in unpaid care—should be rewarded rather than taken for granted.

Policies should ensure that sufficient economic and social resources are given to caregiving, including investing in education and training for the caregivers themselves and ensuring that they are sufficiently compensated for their work. The United States should also maintain an awareness that attracting health professionals in developing nations away from their home countries creates a care gap that may require reciprocation.

Temperance

Temperance encourages policymakers to take the long view in formulating strategies for the dependent elderly and caregivers rather than embracing seemingly easier, short-term solutions. It demands that long-term care solutions be just that—long-term.

If the elderly and their caregivers are strained now, it will only get worse as the age of the population rises. Policies must take into account the growing stress on the health care system, the growing strain on American families trying to care for their loved ones, and the heightened stress for paid care workers whose resources are already stretched thin.

Temperance underscores the problems with shorter-term solutions like recruiting caregivers from overseas by considering longer-term issues such as health infrastructure in the developing nations where those workers are coming from and the need for greater self-sufficiency in supporting a stronger native non-migrant workforce to handle the growing demands. It can help to envision the long-range consequences of cost-cutting in health care. It also recognizes that with the diminishing number of young people compared to the elderly, policies must provide guidance for American

businesses looking for ways to cope with a growing number of workers who also serve as caregivers to their elderly family. A viable, long-term plan will be essential for the success of U.S. businesses and the well-being of employees who are, first, members of families.

Social Justice

Social justice calls for treating people fairly and giving them their due, and it demands that society's institutions reflect and promote justice. This means, most fundamentally, that resources are equitably distributed and that social norms, economic structures, and decision-making processes enable people—particularly the most vulnerable—to exercise self-determination and live under conditions of equality. Indeed, social justice may be the paramount ethical principle for policy surrounding caregiving.

Social justice examines the hidden value of caregiving and the division of care labor and holds that care is at the center of social life and among the most valuable forms of work. Care for the elderly should be considered equal to care for the young, women and men should have equal responsibility in family caregiving, and migrant workers should receive the same opportunities as native caregivers. Social justice demands that we do everything possible to avoid creating and perpetuating inequalities like those tied to ageism, gender, health, and economic stability.

Policies framed by social justice must ensure that the voices of the elderly, and paid and unpaid caregivers, are all heard throughout the policy design and implementation process.

The Plight of the Dependent Elderly

More than 12 million people in the United States currently need some form of long-term care. Around 1.4 million Americans 65 and older are cared for in nursing homes, but the vast majority—roughly 80 percent—are cared for at home or in community-based settings.[3]

Changing demographics are quickly giving rise to a growing need for long-term care. The aging population is growing at a phenomenal rate. From 2000 to 2050, the U.S. population age 65–74 will grow from 18 million to 35 million, the population age 75–85 will grow from 12 million to 26 million, and, most dramatically, the population age 85 and older will grow from 4 million to 18 million.[4] The number of people using nursing facilities, alternative residential care, or home care services is expected to almost double from close to 15 million to 27 million in 2050.[5, 6]

This same trend is expected to hold true in other developed countries. Less acknowledged is that the need for long-term care, not just for the aged but also for other groups including people with HIV and AIDS, is increasing in the developing world—where health care systems may be more fragile and understaffed—at a rate that far exceeds expectations for developed countries.[7]

Inadequate Resources, Inadequate Care

The trend toward longer life in the United States and many other parts of the world might seem heartening, but by all accounts the care that the aged currently receive is inadequate. Ageism pervades many societ-

ies and their health care systems.[8, 9, 10] This affects both the amount and quality of care the elderly receive. Some people argue, for example, that health care resources should be rationed for the elderly and given instead to the young, which can lead to inadequate treatment. And stereotypes about the elderly can leave them facing paternalistic treatment that fails to take their abilities and needs seriously.

The institutions that provide long-term care to the dependent elderly—assisted living facilities, residential care facilities, and adult day care centers—are plagued by a lack of funding, and, in many cases, unsafe conditions.[11, 12] Older people with medical conditions and disabilities living outside of institutional settings also often receive inadequate care. Strikingly, about 20 percent of adults who need long-term care go without it.[13] The fact that most health care for the elderly is provided by professionals with little or no special training in geriatrics, an area of practice that has never flourished in the United States, compounds these problems.[14]

The issue of educated, available health professionals and paraprofessionals, or direct care workers—the front line in long-term care—is a central one. Yet, little political attention has been given to the burgeoning "care gap" as the need for long-term care exceeds the number of caregivers.[15, 16, 17, 18] While the demand for caregivers is increasing, the United States and other nations already face a persistent shortage in the pool of paid caregivers, a shortage that is only expected to grow.

Changes in the capacity of the "informal" support system, i.e., family and other unpaid caregivers, may also worsen the plight of the aging population. Families are having fewer children and are more likely to be distant geographically. More women are employed in the paid labor force than in earlier eras. And in low- and middle-income countries, the migration of women seeking paid work as caregivers—and ultimately better economic opportunity—stands to imperil the elderly and others left behind. Without increased efforts to train and maintain caregivers where they are needed most, we will face a shortage of people to look after our aging parents and grandparents, aunts and uncles, and friends and neighbors.

A Fractured System

The lack of integration, or even cooperation, between different kinds of care—that is, between assorted medical specialties and between acute and long-term care—is also a source of great concern for the elderly and their caregivers. Many elderly people have concomitant conditions that call for attention from a variety of medical and social service professionals. Yet health care tends to be structured in a highly fragmented way rather than around cohesive, inclusive, team-oriented relationships.[19, 20]

A related problem is our health care system's emphasis on acute care. Its objectives and those of long-term care are quite different. While acute care aims to treat and ideally cure patients, long-term care involves the clinical and social management over time of chronic conditions in order to mitigate their effect on people's lives.

Payment structures are also fragmented. While Medicare covers acute care, post-acute skilled nursing care, and post-acute home health benefits, long-term care is paid for by Medicaid or out of pocket. Medicare also pays for acute care costs that are related to unmet long-term care needs.

The Plight of Unpaid Caregivers in the United States

Around 80 percent of long-term care in the United States is provided by unpaid caregivers—usually family members, the focus here—but also by neighbors, friends, and volunteers. In comparison, only 8 percent of those needing care receive it at home solely from paid workers and 14 percent get help from both paid and unpaid caregivers.[21] These caregivers are mainly women who are married or living with a partner. About 42 percent are 50 years of age or older.[22] As noted above, families are facing new challenges given that they tend to be smaller and thus have fewer people available to give care, and tend to be spread apart geographically.

The Social and Economic Value of Caregiving

High demand and low support is an apt way to characterize the circumstances of family caregivers. Even though caregiving is crucial to the functioning of any society, caregiving lacks social standing and garners little respect in the United States. This could be due in part to our nation's commitment to individualism and to ideals like independence and self-reliance. As important as these are to our nation's character, they might also serve to obscure the reality that significant portions of our lives are defined by vulnerability and a need for care. As a result, the needs of the vulnerable and those who care for them—mostly women—become invisible.

In economic terms caregiving is not typically seen as productive, or even as work. Economists have noted that this work is discounted by standard economic theories that exclude things produced in the household, as opposed to the market, and that ignore the transfer of value from the household to the market. Nevertheless, caregiving labor makes a fundamental contribution, or "input," into the processes of production. Research estimates its national worth at over $300 billion.[23, 24] This hints that societies are deeply invested in the highly gendered and unequal division of uncompensated caregiving labor that leads to surpluses and savings in public expenditures, including health care.[25, 26, 27]

The Elderly, Family Caregivers, and the Paid Caregiving System

Family caregivers can be significantly strained by their interactions with the health care system. The health care system's current strategies for cost-cutting in particular—its longstanding underinvestment in workers, organization around acute rather than chronic care, and lack of coordinated and integrated services—have increased the burden on caregivers.

In the past decade, efforts to contain explosive health care costs have included shortened stays in hospital settings and early discharge of patients. This strategy relies upon family members to serve as providers of care in home settings, or a sort of "semi-voluntary conscription of unpaid healthcare workers, who generally lack any professional training for their tasks."[28] At the same time, efforts to control upwardly spiraling costs have included reducing the benefits for home health care from insurers and public programs.[29] As discussed below, cost savings are achieved at the risk of compromising the quality of care the elderly receive and bringing significant harms to family caregivers.

Criticism of the health care system is often aimed at the "medical model" for

its tendency to see diseases and conditions rather than people. When health professionals do see people, their focus is most often on individuals, not the relationships—including those with families—that make them who they are and that may contribute to their care.[30] What's more, given the health care system's weaknesses in providing integrated care, family caregivers have the added burden of learning how to navigate a system ill-suited to care for the elderly in order to ensure that their loved ones get the professional services they need.[31]

Another form of fragmentation is the disjointed relationship between paid and unpaid caregivers. The needs of these groups, to the extent that they are recognized, are often treated as entirely separate areas of concern. Although exclusive family care is the model that prevails, and there are some who only have paid care, for most people family and paid care is in some way integrated.[32] Family members may have a role in hiring aides, and they may supervise the care they provide. Sometimes family caregivers play the primary role, while at other times they complement care given by paid care workers. "There are many different living situations and types of interactions between [home health and other] aides, some infrequent and casual, others intense and prolonged."[33] Whatever the arrangement, family members and paid caregivers are inextricably linked as they work to meet the needs of the dependent elderly. Among advocates and policy makers, however, these systems are usually seen as separate worlds, with independent policy agendas, competing for attention and resources.[34] This ends up weakening an already fragile link between family caregivers and those doing care work for pay.

Finally, families have different capacities to provide for the needs of their elderly, dependent members. Yet rather than provide comprehensive evaluations and pay attention to the particular circumstances of families like the availability of a dedicated caregiver, financial assets, housing situation, communication and decision-making skills, and surrounding social network, health care system policies, programs, and practices such as discharge planning make only "rough assessments" of families' particular capacities to provide care.[35] This leaves many families in precarious situations, distressed at being unable to provide needed care and, in the case of the elderly, potentially facing worsening illness or disability.

The Elderly, Family Caregivers, and the Workplace

In a significant shift from earlier eras, the majority of people working as family caregivers—at least six out of 10—are employed in the paid labor force.[36] There are over 20 million employees with aging, ailing parents in the United States. But for the most part their employers offer little, if any, support. The Society for Human Resource Management, which represents over 200,000 human resource and other corporate officials, notes that only 6 percent of employers have written policies about elder care; 39 percent of its members said that elder care benefits were "too costly to be feasible." While 76 percent say they offer help on a case-by-case basis, when they do, they tend to offer those that cost them little or nothing, like referral services and unpaid leaves;[37] only 1 percent subsidize any elder care benefits.

Beyond what employers make available, caregivers receive some assistance from the Family and Medical Leave Act of

1993. Under the FMLA, workers caring for a spouse, child, or parent with a serious health condition are entitled to up to 12 weeks of unpaid leave each year so long as they have worked for at least year for an employer with 50 or more employees. Some states have more generous family leave policies, as well. Yet these policies still leave many workers uncovered and studies show that it doesn't offer adequate support even for those workers who are eligible.[38, 39] Working-class women and families are especially vulnerable because they are more likely to have jobs with employers not covered by the FMLA.[40]

Prompted by challenges from business groups and criticism from federal courts, the Department of Labor is currently reviewing one of the regulations that implements the FMLA and allows for unpaid leave to respond to family or medical emergencies. Supporters of the FMLA worry that the proposed revision could scale back federal worker protections, leaving family caregivers even more vulnerable. According to data from "The Work, Family, and Equity Index," a just-released study from Harvard and McGill universities on measures ranging from leave for childbearing and adoption, sick days, and available time to care for family members, the United States already provides considerably less than other high-income countries, and even falls behind a number of middle- and low-income countries.[41]

The Plight of Paid Caregivers: An International Issue

Native Caregivers in the United States

The United States and many other countries have found themselves facing a severe shortage of paid caregivers in the last several years due to a declining number entering the field, problems retaining new nurses, and growing trend toward early retirement.[42, 43] Paid care work—also done primarily by women—is now characterized by unprecedented vacancy and turnover rates.[44, 45, 46] This holds true for registered nurses as well as the paraprofessional, or direct care workforce.[47] Given the increasing number of elderly persons, the country will likely face a care gap, or what some call a "care crisis," in part because of changes in the capacity of families, but also because of this persistent shortage of paid caregivers.[48, 49]

Multiple factors explain this shortage. Caring for the dependent elderly involves difficult, often unpleasant tasks and leaves caregivers vulnerable to injury, illness, and infection. And while work environments vary, paid caregivers—nurses and direct care workers like nurse assistants, home health aides, and personal care aides—maintain that, like family caregivers, their work suffers from a poor public image and lack of respect.

They point to larger systematic problems including inadequate staff to support quality patient care, increasing hours on the job, frequent rotation between units rather than continuity, centralized and unresponsive management, a lack of safe working conditions, exclusion from participation in decision-making, inadequate opportunities for continuing education and professional development, and poor compensation. These problems are particularly acute for direct care workers.[50, 51, 52, 53]

Nearly 90 percent of the direct caregivers in nursing homes and home care are women.[54] In 2000, approximately 7 percent of nursing home aides and hospital aides were not U.S. citizens, and

non-citizens represented over 16 percent of home care aides.[55] And these numbers do not capture undocumented workers, a group that may find frequent employment in home care. Many of these paid caregivers are employed part time and hold other jobs for additional income. Only 55 percent of nursing home aids and 46 percent of home care aides work full time throughout the year.[56]

The wages of caregivers are among the lowest for all occupations in the United States. In 2004, the median hourly wage for personal care and home care aides, home health aides, and nursing aides, was $8, $9, and $10 per hour respectively.[57] The U.S. Supreme Court's finding in *Long Island Care at Home Ltd, et al., v. Coke* that most home care workers are exempt from minimum wage and overtime protections poses to make this group even more economically vulnerable. Adding to their struggle is the lack of benefits, including health insurance. One in four direct care workers lacks health insurance coverage. This is because not all employers offer health coverage, self-employed workers lack access to employer health plans, not all employees are eligible for benefits, and many employees do not enroll because of cost barriers.[58, 59, 60]

These problems might be addressed by any number of strategies, but right now a central one is to recruit women from other countries—most of them developing countries—to serve as caregivers in the long-term care workforce.[61, 62]

The Flow of Migrant Caregivers

Foreign-trained nurses entering the United States have increased at a rate faster than that of newly educated U.S. nurses since 1998. The number of nurses trained abroad has more than doubled as a percentage of U.S.-trained RNs, from six per 100 in 1998 to 14 per 100 in 2005.[63] And while many foreign-trained nurses apply for and are offered jobs as nurses in U.S. hospitals, a substantial number end up working as direct care workers in long-term care.[64]

The reasons why women migrate from developing countries in search of caregiving jobs usually echo the concerns cited by paid caregivers in the United States: years of underinvestment in health care systems, low pay, supply shortages and outdated equipment, unsafe working conditions, and little opportunity for continuing education and professional development.[65,66] Although in some cases they are escaping social unrest, or even the threat of violence or persecution.

Current economic policies may be the greatest contributor to the transnational flow of women seeking paid care work. Under pressure from institutions like the International Monetary Fund and the World Trade Organization, many developing countries have opened their health care systems to international finance. Economic and sectoral reform—often accepted as conditions of loans from international lending bodies—have capped spending, frozen hiring and salaries, expanded the private sector, and cut public budgets.[67] This has led in many countries to reductions in health sector employment.[68]

Private employment agencies exacerbate the problem and are becoming major players in the movement of health workers around the globe. Since the mid-1990s, there have been surges in the recruitment of overseas nurses.[69] At present, private U.S.-based agencies are recruiting heavily in India and Sri Lanka.[70]

Some governments also recruit their own citizens for care work abroad. The Philippine government, for example, figures prominently in "the political economy of migration" as the largest source of registered nurses working overseas.[71] The government's policy of facilitating labor migration was, notably, part of the 2001-2004 Philippines economic development plan.[72] Along with the Philippines, India and China have also come to see human capital—including care workers—as a legitimate export.

Along with the roles played by international lenders and for-profit agencies that cross borders, shifting immigration strategies are still another factor. In the United States, once-restrictive policies are giving way to ones that promote the flow of migrant health workers, including some nurse categories.[73] In 2005, the United States passed the Emergency Supplemental Appropriations for Defense, the Global War on Terror, and Tsunami Relief, which included approval for 50,000 new visas for nurses. And in the Senate efforts have been underway to pass legislation that would remove the numerical cap on foreign nurses permitted to migrate to the United States. Employers and industry organizations like the American Hospital Association who are eager to gain access to migrant nurses and other health workers who will work for reduced pay and benefits are lobbying strongly for the passage of these measures.[74] Selective immigration policies like these are a strategy increasingly being used as an "instrument of industrial policy."[75]

Shifts in health sector policy also appear to play a key role in shaping demand for health workers like nurses and direct care providers. During the early to mid-1990s, nurses suffered from falling or stagnating wages and schools of nursing began sending out fewer graduates; from 1995 to 2000 there were 26 percent fewer graduates. These trends can be attributed at least in part to the move toward managed care, a shift in health policy that constrained growth in hospital positions for RNs and more generally depressed the market for nurses.[76] When managed care fell out of favor, however, the United States saw an expansion in the number of nursing positions, inside and outside of hospitals. Migrant nurses now fill many of these positions.

Implications of the Current State of Caregiving

By taking an ecological view, we have identified a complex configuration of social, economic, health, labor, and immigration policies that threaten the health and well-being of paid and unpaid caregivers, the dependent elderly, and, on a larger scale, both developing and affluent countries. Here are some specific concerns we can identify:

Unpaid Caregivers

Families and other unpaid caregivers confront a number of major challenges. The lack of attention to and support for their social and economic contribution as caregivers ultimately leads many women to feel isolated and unvalued, and, in some cases, to defer or abandon social opportunities and their own aspirations—clear threats to their dignity and the principle of social justice.[77] Yet if cost cutting in health care persists, unpaid caregivers will continue to be conscripted as a "standing reserve of labor for the health care system."[78]

Modern health care needs are also likely to require untrained, unpaid caregivers

"to provide more hands-on, often technologically complex care; and undertake greater burdens for longer times…"[79] If poor working conditions and the shortage of paid caregivers continue, this will only escalate as an issue. Unless we address the fragmented structure of health care, family members will continue to navigate a system that is ill-equipped to serve their loved ones, undermining such values as beneficence and reciprocity.

Caregiving by those working outside the home in the paid labor force often leads to distress and distraction at work, frequent absence, use of unpaid leaves, and even early retirement. Not only are these caregivers frequently thwarted in terms of career advancement, a substantial percentage of these (mostly female) caregivers are vulnerable to financial hardship over time due to reduced wages, pensions, Social Security, and other retirement savings vehicles.[80, 81, 82] And those not employed in the paid labor force face even more serious economic insecurity over time. The median annual income of caregiver households, roughly $37,000, is only 85 percent of the national medium of $43,500.[83, 84]

There is reason to believe that the economic circumstances of unpaid caregivers might worsen. Studies suggest that a growing number of adult children are now paying for their aging parents' housing, medications, and other costs. Some find themselves depleting their own savings. If health policy dictates more cost cutting, family and other unpaid caregivers will face greater "pressure to pay more direct costs."[85]

Numerous studies show that family caregivers live with chronic stress and are at heightened risk for poor physical health, depression, and death, putting justice, beneficence, compassion, and temperance all at stake.[86, 87, 88, 89] These caregivers spend less time taking care of themselves, seeking out preventative care, trying to maintain a healthy diet, exercising, and getting adequate sleep. The fact that those who are not employed in the paid labor force or who work part time in the United States often lack health insurance adds to this vulnerability.

Paid Caregivers

A significant percentage of female paid caregivers report significant stress, which is compounded by a shortage of colleagues and adequate training—unsurprising due to the paltry pay and poor working conditions. Many also suffer from poor health and the absence of health insurance. Given their low pay and often lack of benefits, they face serious economic insecurity.[90, 91] Many U.S. educated caregivers also argue that increased reliance on nurses from abroad serves to keep wages and benefits low and working conditions poor. And in the absence of "career ladders," they have little opportunity to improve their situation. All told this weakens respect for human dignity, justice, and reciprocity.

For those who leave their home countries in search of employment in the United States, it is far from clear that migration enhances their life prospects.[92, 93] Most would prefer not to leave, and many experience the adverse effects described generally as dislocation. Employment experiences vary considerably, but health workers often stand to suffer the same hardships at their jobs in the United States as they experienced at home.[94]

Migrant caregivers often get lower-tier jobs—and thus lower pay and fewer ben-

efits—than they are promised by unscrupulous recruiters representing for-profit corporations. Depending upon the terms of their visas, they may have to return to their countries of origin and, as a result, often rotate in and out of jobs, losing anticipated opportunities for advancement. Some migrant caregivers also face discrimination and other indignities as immigrants, yet cannot voice these or other concerns related to the conditions of their work.[95] And as they care for the dependent elderly in the United States, these workers from abroad lose time with their own families, many of whom suffer their own care gap.[96]

Developing Countries

Source countries, those nations from which women migrate, may receive the greatest gains from remittances sent back by caregivers working abroad. Women in particular have a reputation for reliably sending money back to their families. In terms of economic growth and development, remittances have exceeded the amount of official development aid flowing into source countries.[97, 98]

Yet source countries and their citizens have much to lose. The migration of caregivers both reflects global inequalities and perpetuates them. Source countries' investments in education are effectively lost for those caregivers who are educated at home yet work abroad permanently. The same is true for those who do return home, yet come with skills that are not applicable to their countries' needs and/or capacities.

Perhaps the most obvious loss is in the health system capacity. Persistent losses in available health services and staff contribute to and ultimately worsen global health inequalities, raising serious concerns of justice.[99] Shortages in health personnel are said to be the most critical constraint in achieving the United Nations Millennium Development Goals and the WHO/UNAIDS 3 by 5 Initiative.[100, 101] Losses to migrant caregivers' communities and families are also significant, where the elderly members may need care.[102] Losses in intellectual capital can also over time hurt source countries' innovation, national economic investment, and economic development.[103, 104]

Affluent Countries, the United States

Affluent nations benefit from the global organization of caregiving because they get cheap labor and relief from labor shortages—at least temporarily. They may also gain substantial savings by not needing to invest in the education of caregivers or in the health and social services sector.

Yet the current organization of caregiving also has detrimental effects for developed countries. The restricted nature of family leave policies creates significant costs for employers. Full-time employees who serve as caregivers for elderly family members "cost" U.S. employers approximately $34 billion in 2004 due to absenteeism and workday interruptions, a 16 percent increase from 1997.[105] Moreover, the limitations in existing policy, coupled with the strategies for cutting health care costs like early discharge, contribute to long-term economic insecurity for many women who must cut back on or even leave their jobs—a consequence that may require them to draw upon public assistance in their later years. The adverse effects on caregivers' health could also increase health care spending in the United States. And if members of the conscripted team of unpaid caregivers were to

collapse under the strain, this could put even more pressure on already-stretched government programs like Medicare.

Still another set of concerns arises from the United States' reliance on caregivers from other countries. This can, over time, undermine investments in education and training for nurses and direct care workers and also thwart efforts to improve wages and working conditions for caregivers. These consequences ultimately serve to threaten the country's intellectual and economic vitality. Drawing in caregivers from developing countries could also have important health consequences in the United States to the extent that we diminish the health system capacities of other countries, increasing the danger of transnational pandemics.

The Elderly

Finally, what are the implications of the current organization of caregiving for the dependent elderly? Given the organization of caregiving, they are likely to be seen as a burden, their needs are likely to be overlooked or misunderstood, and they are at risk for being cared—if they have the benefit of being cared for—under precarious conditions despite the extraordinary efforts of individuals. As we have shown, this is what much of the available evidence reveals, and we can good reason to expect that it will worsen without a coordinated, committed policy response.

Current Efforts

Some efforts to address the escalating concerns of the dependent elderly and their caregivers have already begun. Although all are good first steps, none are sufficient to deal with the existing care gap, much less the growing need for care.

The passage of the FMLA was a key step toward recognizing the need for policies that protect the dependent and their families. Yet the FMLA does not offer sufficient coverage for caregivers and is at present under attack. Prompted by challenges from business groups and criticism from federal courts, the Department of Labor is reviewing a provision of the FMLA that allows for unpaid leave to respond to family or medical emergencies.[106] The department is seeking comments on a series of questions regarding covering intermittent FMLA leave, including the definition of "eligible employee," the definition of "serious health condition," and leave determinations/medical certifications. Supporters worry that this discussion could lead to weakened worker protections rather than stronger protections for all caregivers.

Along with the FMLA, we can point to a few other efforts. The Older Americans Act, originally enacted in 1965, was reauthorized in 2006. Along with its other provisions, the OAA Amendments of 2006 include support for Naturally Occurring Retirement Communities, which promote the practice of aging in place. NORCs are seen as "helping older adults age with dignity."[107]

The OAA Amendments of 2000 established another important program, the National Family Caregiver Support Program, developed by the Administration on Aging. This program gives states funds to provide information, assistance, counseling, respite care, and other services to family caregivers. And the 2000 amendments also established the Native American Caregiver Support Program.

The last few years have brought signs of renewed interest in Congress on these

issues. The Lifespan Respite Care Act authorized competitive grants to states to make quality respite care available and accessible to family caregivers. The bill, passed last year in the Senate, currently awaits funding.

The Healthy Families Act currently under consideration would require some employers to provide a minimum number of paid sick days each year for certain employees to care for themselves or a family member. And even though its focus is on parents with children, it is worth noting the Family and Work Balancing Act. This bill is aimed at parents and includes provisions for paid leave as well as support for child care and after-school care.

States have also undertaken efforts to address caregiving concerns. Initiatives are underway to respond to the concerns of direct care workers, nurses, and family caregivers. Initiatives for direct care workers include increasing access to health insurance, enhancing wages with pass-throughs and minimum wage ordinances, developing worker training programs, and collecting data on care providers. State-level efforts for nurses include offering financial aid for public-private nursing education partnerships between universities, giving incentives for home ownership aimed at improving recruitment, and improving working conditions for nurses to address retention concerns with measures such as flexible staffing, no mandatory overtime, and support for career ladders so that workers can improve their skills and advance professionally.

Some states have also expanded coverage beyond that provided by the FMLA by broadening definitions of who counts as "family," lengthening leave periods, and extending leave to employees in businesses with fewer than 50 workers. Several states also offer refundable or non-refundable small tax credits for caregivers. Yet states are finding it challenging to shift their thinking and services toward providing support for family caregivers as "consumers" rather than just to the older person who is receiving care.

Conclusion: A Path Forward for Care

A greater understanding of the circumstances confronting the elderly and their caregivers, and in turn, the nation, can enable us to move from ethical principles to specific policies. Given that who gets care and who gives care under what conditions, and with what resources, is the result of social, economic, and health policies shaped by an array of decision-makers, it is challenging to determine who is obligated to help and how. Yet the ethical seven principles outlined here provide both a blueprint for developing policies and a framework for evaluating them.

An Ecological Ethic

An ecological ethic emphasizes the multiple and complex interconnections that, combined, link together the elderly, family caregivers, and direct care workers and shape their lives. Just as ecologists study of patterns in nature, how those patterns came to be, how they change, and why some are more fragile than others, policymakers should see caregivers and the elderly as interdependent; affected in patterned ways by shifting social, economic, health care, labor, and even immigration policy choices; and above all, vulnerable to varying degrees.

An ecologically-minded ethic aims to address fragility and to promote sustainability in the policies and systems surrounding the elderly and caregivers. It aims to ensure that caregiving is organized in a way that secures integrated, quality care for some elderly and supports and advances the well-being of those who care for them.

An ecological ethic therefore calls for designing integrated policy strategies. This requires asking such questions as: How can labor policies promote quality care for the elderly? How can we design employee leave policies that support women's long-term health and economic security? How can cost cutting in health care and increased support for the elderly and caregivers co-exist? And how can we coordinate labor, health, and immigration policy choices to better manage the migration of nurses, while supporting the native workforce?

Respect for Human Dignity

Respect for human dignity should take the form of policies that acknowledge that most elderly persons want to be as independent as possible. They should also ensure that the elderly and their families have the information they need to make informed

choices about the kind of care they will receive and provide diverse programs and services to accommodate a wide range of ability levels.

Respectful policies should also recognize that family caregivers live in a variety of circumstances and need different kinds of supportive resources. Ongoing and additional investment in NORCs, respite care and counseling services for the elderly and family caregivers, and information about long-term care options could help to promote this principle.

Mending the patchwork health care system and designing more coordinated, integrated care that is attuned to the needs of the elderly would allow them and their caregivers to better manage care according to their own goals, thereby promoting respect for human dignity. The principle also calls for ensuring that all people have affordable health care coverage, including those who are working outside the paid labor force. Career ladders for paid care workers—already under development in some states—are still another area for policy reform aimed at promoting respect for people's ability to pursue their goals and to strengthen their knowledge and skills.

Beneficence

Beneficence requires investment into the education and training of long-term specialists so that they too can provide care that offers more benefit to the elderly. Like existing efforts, this could take the form of student loans, investments in educational institutions and programs, or pay incentives. This principle, like respect for human dignity, also supports a reformed health care delivery system so that the elderly and their caregivers benefit from their encounters.

Beneficence supports the design of policies that better ensure the safety of the elderly, wherever they reside. Adequate investments in recruiting and retaining health care professionals, particularly direct care workers, and identifying new pools of caregivers are essential elements of ethical policy. And gaining governmental support for re-organizing the health care system around the goals of long-term care is essential to moving all of these goals forward. Incentives for reforming health system practices like discharge planning would be part of these efforts.

Beneficence also demands that caregivers not suffer social, financial, physical, or psychological harm as a result of their efforts. Employee leave policies that provide meaningful supports to workers who are caregivers as well as health care and retirement policies that provide for those who leave the paid labor force to work as caregivers are important areas for policy intervention. The current context requires expansion rather than contraction of family leave policies.

Paid caregivers, like direct care workers, need labor policies aimed at improving wages, health insurance coverage, and working conditions, as well as equal protections both for themselves and those receiving care. Policies must be structured with the interests of both the caregivers and the care receivers in mind.

Beneficence also holds that the United States must design health policies that ensure care for its population and good jobs for its workers. Yet it should not unfairly burden poor countries by encouraging the migration of caregivers through calculated shifts in immigration policy or the proliferation of unethical recruitment practices that can harm other countries

and erode working conditions in the United States. Governmental incentives to employers who engage in fair recruitment and hiring practices warrant consideration for the benefit of both U.S. and foreign-educated caregivers.

Compassion

Policies can help to create the conditions that enable paid caregivers to treat the elderly with the compassion they deserve. One example would be adequate staffing levels in institutions for the dependent elderly and sufficient training for direct care workers. Another, already mentioned, would be stronger leave policies for employees tailored to the demands of elder care. These would encourage employers to treat workers who serve as family caregivers with compassion. Strengthened support for respite care and caregiver support centers also promotes this value.

Reciprocity

Policymakers should ensure that sufficient economic and social resources are available for caregiving and be mindful that many people cannot go it alone when it comes to aging or caring for the dependent. Investing in an educated and committed pool of caregivers is crucial.

Creating policies that acknowledge the condition of unpaid caregivers by adequately compensating them for the important work they do is also central to reciprocity. This could take many forms: tax credits, direct subsidies or stipends, or perhaps credit time for Social Security—all options that merit further exploration.

Due to the extent that the United States relies on caregivers from other countries, we should also consider ways to reciprocate. One example would be helping to support the development of health care infrastructures in developing nations and training additional caregivers.

Temperance

Temperance reminds policy makers to take the long view when formulating strategies for the dependent elderly and caregivers rather than embracing seemingly easy, short-term solutions.

For example, health care cost-cutting clearly leads to more care from family members, but rather than allow the burden to be shifted onto unpaid labor, policy-makers should develop strategies to bolster the health system and better prepare families for their caregiving responsibilities. There are also shortages in the pool of paid caregivers, but rather than relieving it with a migrant workforce, we should look for sustainable alternatives like educational and salary incentives for native workers. The key lesson of temperance is that we need to strengthen our self-sufficiency in the caregiving workforce and improve working conditions so that over time the quality of elder care can improve.

Social Justice

Social justice, like many of the other principles, calls on us to ensure that sufficient resources are allocated for the care of the elderly and the support of paid and unpaid caregivers. It also demands that we respond to problems such as ageism, the gendered and unequal distribution of caregiving labor, and the notion that caregiving does not constitute a meaningful social or economic contribution. Areas that need particular policy intervention are the gendered and unequal

distribution of caregiving labor and the persistent wage gap between men and women.[108] These imbalances mean that many working women are the primary ones to leave the paid labor force and take on the role of caregiver, given their typically lower contribution to household income. Creative policy innovations that tackle this and other issues should be identified and supported.

Social justice also requires us to listen to the voices of the elderly and caregivers at all levels of the policy making process. Effective mechanisms for soliciting the ideas of these groups are critical to the successful functioning of society and its institutions in the future.

Considered in a global context, justice also calls for ensuring a fair distribution of caregiving resources around the world so that we avoid perpetuating inequalities in global health. Caregiving is clearly an international responsibility. When it comes to the specific issue of health worker migration, many governments have explored and implemented policies aimed at managing migration so that both sending and receiving countries benefit and workers are afforded protections when it comes to the practices of recruiters and employers. The United States so far has not engaged in this effort despite the fact that it is the country receiving the most migrant nurses.

The seven ethical principles of caregiving require the government to take a central leadership role in ensuring that fair and sustainable practices are developed in the coming years. Important policy initiatives already underway can be more systematically supported and further innovations can be encouraged with the support of policy makers. Employers, professional associations, advocacy organizations, international lending institutions, and trade unions all have particular contributions to make according to their scope of action, their skills, resources, and powers. The federal government can help shape and encourage these practices to ensure that they develop into sustainable, long-term solutions. A socially and economically vibrant America calls for nothing less. And our values, including our love for the generations that came before us, require it.

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