

*Dependency, Difference, and Global Ethic of Longterm Care*

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**Introduction**

I recently attended a bioethics meeting on the topic of dependency and health-care which was held in the offices of Partners for Care, a public agency employing home healthcare aids for New York City as the careworkers concluded a successful strike for improved wages. The halls filled with women who, speaking in an English inflected with a Caribbean accent, praised the “mighty God” and “on-time God” they served. The women seemed to be cut of one clothe: all aged between twenty and fifty, all women of color, black or brown, with a sprinkling of Latinas and Asian woman. In the conference participants, in contrast, were mostly white, middle-class and had advanced educational degrees. The women outside, who were engaged in exactly the work the people at the conference pondered how to improve the conditions under which people received and gave long-term care, these women were doing what it took to bring about the improved conditions: They had managed to get better, if still not fully adequate, pay.

The contrast between conference members and the women in the halls bespoke the division of labor we see within the United States, and with some variation, in industrialized nations of West Europe and wealthier areas of Asia. The gender, racial, class, and immigrant status of these careworkers are typical of paid careworkers globally. The professional men and women in the room were beholden to these women for the longterm care of their own family dependents and for the longterm care of the dependents they worked with professionally.

Long-term care is a health issue, but it as much a public health problem as it is a clinical medical or nursing problem. It is both a social problem as well as a personal or family problem; and it certainly is as much a global issue as it is an issue for any one country or type of economy.

Feminists have talked a great deal about childcare. While arguably childcare is a form of longterm care, these longterm careworkers were ministering to the longterm care needs of the elderly, by people with serious chronic illness, or by people who have

impairments of the sort that render or label them “disabled.” In countries, where childcare arrangements have made their way into the national agenda, women still find themselves burdened with care responsibilities. Now it is their elderly parents, or a spouse or adult child who has been disabled by accident or illness, who need their care.

While each form of care has its own set of problems and concerns, childcare and longterm care are importantly intertwined. The healthcare aides, who spend most of their days caring for frail elderly went on strike so that they could better provide for the dependents that they care for in their own homes, their own children and, not infrequently, their own elderly family members. The Filipina working in New York City who is caring for an elderly person or a child of a working couple may have left her own child back in the Philippines. The personal assistant who is allowing a disabled adult in San Francisco to function “independently,” may have left behind family members in Mexico who need care. Barbara Ehrenreich and Arlene Hochschild argue that the solution to the care crisis in wealthy nations is giving rise to a crisis of care in the poor nations. They focus on childcare, and touch on other longterm care. But, the focus has begun to shift to the elderly and other adults with longterm care needs world-wide.

Increasingly, obligations of familial caregivers need to be supplemented by non-familial caring, whether these more formal caregiving arrangements are provided through state-funding, NGO’s, religious and charitable institutions or workplace accommodations. This means that paid caregivers and professionals must do a growing proportion of caregiving. It also means that we require structures that will support individuals to the extent that they can be “self-carers” (in that they are self-administering medications, themselves tending to handicap equipment, etc.). And it means that we need a way to articulate the moral dimensions and principles that ought to guide relationships between caregivers and their charges, and relations between the larger community, be it the local community, the nation-state, or the world community.

The situation of long-term care not only raises, but also transforms, many questions that arise with respect to the relationship between caregiver and those cared-for

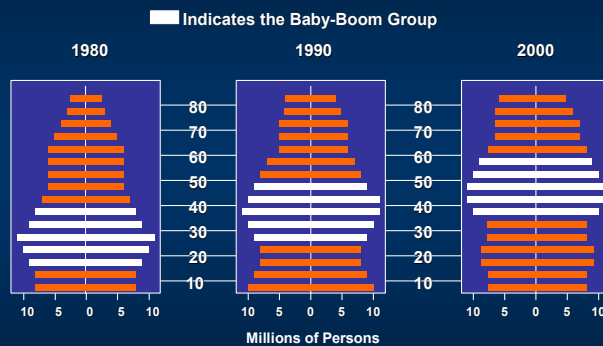
in discrete care-giving situations. What are the ethical responsibilities of the caregiver to their charge in the short-run and in the long haul? When, if ever, are these responsibilities overridden or limited by the responsibilities of caregivers to other individuals, to other institutions (including state and religious institutions), or to oneself, especially where the caregiving responsibilities continue without a clear terminus short of death? What, if any, are the responsibilities of those cared-for to those who are caregivers? Are there special responsibilities that arise from long-term caring relations? How do obligations and responsibilities differ in the case of familial caregivers and professional caregivers—or among different sorts of professional caregivers? To what extent do the obligations and responsibilities differ according to factors such as: the population requiring care, the source of the condition giving rise to the need for care, the extent of the care required, cultural and religious conventions and principles, and the specific economic and social conditions in which the caregiving takes place? Are there ethical codes of conduct we can define, or are situations of caregiving too contextually specific to be amenable to a principled and universalistic approach? If universal defined codes of conduct are not possible, what can we substitute to guide and assess the ethical behavior of and toward caregivers in different circumstances? Although the need is universal and global; the solutions will have to be tailored in accord with local values, resources, and institutions.

The importance of the issue of longterm care hardly requires elaborate discussion. In the United States alone, demographic statistics indicate a steadily growing demand for long-term care services that will peak around mid-century and will overwhelm the system as it is set up today. The same is true for much of the aging world. Demographers have devised what they call the ‘dependency ratio,’ which is “the sum of children and elderly

people divided by the working-age population.” It provides a standardized measure by which we can assess the demand by those requiring dependency care on those who are available, either professionally or informally to provide it.<sup>i</sup> The only group in which the projected increase is only very slight is Sub-Saharan Africa, which is projected to have large increases in its population that offset in large increases its dependent population. In contrast, China will, by some estimates, have one person requiring daily help for every five persons who are employed. (Note however the unquestioned assumption that the class of individuals dependent on care does not overlap the class comprised of the working population, an assumption that needs to be challenged both in theory and in practice.) Add to these demographic shifts the changing role of women, the transnational and rural-to-urban migrations of care workers, the AIDS pandemic and armed conflicts, and we see that the question is not whether, but how, current systems will have to change in order to meet the need.

In the United States, where the current system does not even provide well for the needs of today’s population, and government policies have created a chronic fiscal problems, the crisis is, in fact, already upon us.<sup>ii</sup> The relevant demographics in the United States are conveyed in the following figure, which indicates changes in age distribution from 1980 to 2000. It is evident that the aging of our population will result in increasing problems with longterm care for the elderly.<sup>iii</sup>

## Changing U.S. Age Distribution



AMARA et. al., [Looking Ahead at American Health Care \(1988\)](#)

Why have the groups who are and will be most vulnerable so far not responded to the dangers, limitation, and looming crisis of long-term care? Clearly, there is a lack of public vision. But beyond this, long term care policy suffers from a lack of an ethical foundation, one in which dependency is acknowledged and care is value.

The ordinary policy making process is not functioning well in addressing the future of long-term care needs, financing, and delivery. It cries out for a better clarification and articulation of the values that underlie citizens' concerns, expectations, demands, hopes and fears concerning long term care in their own personal future and in the lives of their loved ones and it calls out for an ethical framework in which these concerns can be cast.

In this paper I want to explore a number of issues that demand the attention of all those interested in questions of care and longterm care, and of justice, locally and globally. I will draw few conclusions, presenting instead what I and my colleagues at the Hastings Center, Bruce Jennings and Angela Wasunnu propose to be an urgent need: the formulation of a globally pertinent ethics of longterm care. I begin by exploring the importance of dependency concerns to those who are disadvantaged or oppressed by a that is by a politics that does not take group difference sufficiently into account in considering needs, and determining principles. For these groups a "politics of difference" has been an important way to articulate the demands of justice. I explore the question of dependency with respect to these groups because, in the distribution of the benefits and burdens of care, these are the people benefit least and are burdened most. They are most

likely to be disadvantaged by a failure to recognize difference with respect to values around issues of dependency and care. A global ethics of longterm care often involves members from several of these groups and will do well to build on a commonality of needs but will also need to need to negotiate differences that give rise to conflict.

I then lay out the project of coming to a global ethic of care as we see it now. I conclude by raising the difficulty of forming alliances between parties who have similar needs, but conflicting interests. To illustrate the problem, I want to face the question of the invisibility of the caregiver of disabled people who insist on the right to be independent.

### **Part 1: Dependency as the “elephant in the room”**

By “care”, in the context of this paper, I mean the support and assistance one individual requires of another where the one in need of care is “inevitably dependent” that is, dependent because they are too young, too ill or impaired, or too frail, to manage daily self-maintenance alone. Such care is more appropriately called “dependency care,” for care is a much broader term and encompasses the services a person could, but chooses not to, provide for themselves. Elsewhere I have called such care “dependency work,” to emphasize that care is a labor; it is work even when it goes unremunerated. Although the dependency care/work of which I speak is largely a hands on affair, it can include the role of supervising and financially supporting such work, if this role includes assuming responsibility to take over the hands on care in the absence of other caregivers. Thus, a mother who guarantees the quality of the hands on care for a dependent child, even when another normally provides the daily hands on work, and who remains responsible for the hands-on care of that child in the absence of another capable person, is still engaged in

dependency work. Thus a mother, who has another take care of her child while she is otherwise engaged, is still the primary caregiver for child. To borrow the language employed by a cooperative of disabled people in Sweden, she is the “service guarantor” for her child’s care even when another is assisting the child.<sup>iv</sup>

Dependency in the form of dependency care has been, is, or is likely to be a feature of all our lives. However differences in ability, race, gender, sexuality, religion, culture, and geography orient us differently towards “inevitable dependencies,” making questions concerning the giving and receiving of dependency care a matter of social, moral and political import. Marx reminded us that we are creatures who have a “species being.” Our lives are interwoven with, and a consequence of, the lives and labors of those who preceded us and those who are our contemporaries. But the interdependencies of which he spoke become reified in products, which then circulate in an economy, manifesting the pertinence for these forms of interdependence for just social arrangements. But despite the reach of “inevitable dependencies” into our lives, and despite the significant economic impact of professional care labor<sup>v</sup>, these dependencies go largely unacknowledged. As a result of feminist scholarship, we have come to understand that the invisibility of human dependency and dependency care is in part a product of a private-public distinction that places a premium on the public and relegates issues of dependency to the private domain. But we can ask if the private public distinction is itself a product of our deep denial of the inevitability of human dependency. Within the theoretical literature and political life of the Western industrialized nations, at least, we are captives of the myth of the independent, unembodied subject—not born, not developing, not ill, not disabled and never growing old – that dominates our thinking about matters of justice and questions of policy.

It is the independent unembodied subject who represents the ethical subject and the political subject or citizen. Yet it is safe to say that the fact of human dependency is the elephant in the room of discourse around many ethical, social and political issues. While the person who does carework is often subordinated and exploited in doing so, when carework is directed at an individual who is inevitably dependent, it differs from work that one person performs for another merely because the one-served has the power to compel the one-serving to perform it. Furthermore, when carework is directed at the inevitably dependent person, the sacrifices it demands of the careworker are not morally supererogatory, but morally obligatory. It is the fact of inevitable human dependency that makes caregiving directed at a dependent neither supererogatory nor merely the needless subservience of the unwilling slave, the underpaid servant or the compliant wife.

### **Dependency as a factor in the politics of difference**

Caregiving is as necessary as human dependency are inevitable. The effect of this simple fact on political and social organization and global and structural injustices of sexism, racism, discrimination against people with disabilities and against the aged, while

often unacknowledged is nonetheless very far-reaching. These considerations need to inform a global ethics of longterm care for each of the differences we will explore are encountered in the dynamics of global and local interactions around longterm care issues.

Iris Young has recently distinguished two aspects of a politics of difference.<sup>vi</sup> The first she dubs “structural inequalities.” People with disabilities, persons of color, and women, are disadvantaged because they begin with different starting points in the competition for the benefits and burdens of social cooperation. A politics of sameness that insists on equal access and opportunity but ignores the differences in starting points can exasperate and perpetuate disadvantage. Thus a politics of difference is needed so that the inequalities can be addressed, providing genuine equality of opportunity and access. The second form of the politics of difference she calls “societal cultural.” It addresses primarily forms of oppression experienced by gays and lesbians, ethnic and religious minorities, and those who demand recognition of their differences to dignify their difference and give them equal standing rather than to equalize their opportunities.

Dependency concerns are largely a matter of structural inequality, although they play an important role in the societal cultural forms of injustice as well. Both play an important role in the global injustices and problematics of longterm care. One should perhaps say that the inequitable distribution of the giving and receiving of dependency care is itself a prime form of structural inequality.

Also important to justice is the recognition of the different ways in which care is given and compensated, the different families and relations in which dependency care is given, and the different cultural values by which care is constituted. Let us consider these concerns in relation to different groups included in a politics of difference.

## i. Disability

People with disabilities are affected in multiple ways by dependency concerns, not all obvious to the able-bodied. It is not only the case that some people with disabilities are especially prone to the vulnerabilities of inevitable dependency, it is also the case that people with disabilities are thought to be or are constructed as dependent in ways in which they are not or need not be. Having access to wheelchairs and living in a place where buildings are accessible reduces the dependency needs for those with mobility impairments. Around the globe, not only are there many disabled people whose dependency needs go unmet, there are also many who are dependent in ways they would not need to be if resources were devoted to equipping them and their surrounding properly, and there are many more who would not be disabled were better health and environmental policies in place. When we speak later of the crisis of longterm care, we would do well to remember that the prevention of disabling conditions, and the elimination of unnecessary dependency should be the goal of global policies for longterm care. For example, resources, to support institutions for the blind, would be better spent providing the blind means to function in society and demanding that nations provide Braille signing and other facilitations and reasonable accommodations. At the same time, preventing blindness that results from treatable diseases, which is an unalloyed good, should not be conflated with preventing blindness by aborting blind fetuses or tolerating the infanticide of blind infants, which may bespeak an intolerance for human variation. A global ethic of longterm care should have the resources to argue for the importance of utilizing resources to maximize the dignity and inclusion of persons with varying capabilities, encouraging policies that replace custodial care with the development of a persons' capacities, but also have the resources to argue for the provision of care as care is needed. *And* a global ethic of longterm care should have the means to argue for the prevention of impairments caused by injustices and negligence, without encouraging the devaluation of those who have disabilities.

Both needing to have dependency needs met which go unmet, and being presumed to be dependent in ways that one is not or need not be exclude disabled people from full social participation and the possibilities of flourishing. Furthermore, people with disabilities are often thought to be disqualified from caring for dependents when in fact they do take on these responsibilities. When, because of prejudice, ignorance or lack of supports, people are prevented from assuming responsibilities they otherwise want to and could assume, they are shut off from a mode of flourishing to which they should have a right. Moreover, the favoring the goal of independence cuts off those who have mental impairments even more completely than those with physical impairments from active

participation in a full life. By stigmatizing dependency rather than dealing with fact of and the variety of human dependency needs, we deny people with disabilities the respect and opportunity to flourish that is everyone's due.

## ii. Racism

As the scene with which I opened these remarks makes vivid, racism is implicated in the organization of dependency work. Paid dependency work is largely carried out by women of color, and among men, disproportionately by men of color. The pay poor, the working conditions enforce what Iris Young has called "the oppression of powerlessness"<sup>vii</sup>, and their recruitment into paid dependency work not infrequently leaves their own dependents at risk of receiving less than adequate care. In the United States, Dorothy Roberts has shown how African American children are disproportionately removed from their families by the child welfare system, and how African American women, while called on to care for white children are often viewed as inadequate caregivers for their own.<sup>viii</sup> The health care aides, many raising families on their own, can scarcely provide for the care of their own children on their low wages and poor benefits. Nor, in the United States at least, are their own dependency needs addressed as they themselves frequently lack the health insurance that pays for the very care they provide to others.

Particularly of consequence to the concerns of this paper is the fact that many of the health care aides in the hallway were immigrants. The importation of care workers, be they health care aides or highly trained nurses have a global impact. Rhacel Salazar Parrenas<sup>ix</sup> has documented that the migration of women from the Philippines and other developing nations result in still poorer women having to care for the dependents of the women who leave. The children of the poorer women are often left to fend for themselves. Neither the children whose mothers often do not return to their homes for a span of ten or more years, nor the children of careworker's nannies, that is the children of the poorest women, fare well.

I have elsewhere<sup>x</sup> argued that a condition of justice for caregivers is that they themselves should be seen as deserving care, that we have an obligation to the caregiver no less than the cared for. Caring is an asymmetrical relationship in which the cared for is frequently not in a position to reciprocate what is provided by the caregiver. Just reciprocal relations require that a third party provide for the caregiver what neither the cared for nor careworker can provide for herself as she turns her attention to the cared for. A third party needs to compensate her for her labors and the deferral of her own needs and interests necessary when one is providing care for a dependent. I speak of this as a principle of *doulia*, borrowing the term from the name of the postpartum caregiver, a *doula*, who cares for the mother as the mother cares for her newborn. I speak of *doulia* as a concept captured in the common saying: "we are all some mother's child." Just as the mother cares for a child she values so that she willingly meets its needs rather than her own, the mother too is a person whose value has been conferred by a mothering person. In recognizing the mother's value we honor the caring labor of the mothering person who

nurtured her. The idea that we are all some mother's child captures the importance of a robust *relationship* of care. Those who engage in paid care labor are not treated caringly, and arguably justly, even when well compensated if their work must be at the expense of other centrally important relationships of dependency.

The work of both Roberts and Parrenas testify to the damage done to these relationships of dependency under current working conditions of many immigrant, migrant, and African American women. Of special poignancy are the stories recounted in Ehrenreich and Hochschild's collection, *Global Women*,<sup>xi</sup> who come to give the love they cannot give to their own children to those of their employers' children and, we might add who give their care and attention to the elderly parents they are paid to care for even as they have to withdrawn that loving care from ailing parents left behind in their native countries.

Hochschild speaks of the "global heart transplant" at work in the exportation of care from poor to wealthy nations.<sup>xii</sup> Racism helps obliterate the full recognition of the humanity of the careworker by erasing the awareness of her relations to her own dependents. A global ethics of longterm care must address not only the conditions of injustice that result in these distributive wrongs, it ought also to address the racist impulses that make rich white consumers of carework oblivious to the importance of relationship in the lives of the persons of color they employ.

The migration of skilled careworkers, such as nurses from developing nations to wealthier nations adds to the devastating impact on the healthcare and long-term care needs of the populations they leave behind.<sup>xiii</sup> These migration patterns are part of the economics of globalization. The gap between rich and poor nations has widened into an ever-increasing chasm. In 1960, the gap between North and South was 20-fold. By 1980 the north was 46 times as rich as the south. In 1999 sixty countries were *worse off* than in 1980.<sup>xiv</sup> Just as rich countries are demanding workers to do care work, women in poor countries are responding in an attempt to escape impoverishing conditions in poor nations.

Beyond the fact of migration, Ofelia Schutte<sup>xv</sup> and others have shown, neoliberal globalization policies affecting nations largely populated by brown and black people, have demanded "restructuring" of government services which have left women with more dependency burdens and fewer resources with which to cope. Domestically and globally the burdens of dependency fall hardest on those who otherwise are oppressed by racism and poverty.

### iii. Sexism

The link between the exploitation of women and caring for dependents is surely not news. The list of feminist works exploring this connection is now too long to list. I, among others have argued that women's failure to achieve equality, despite the removal of legal barriers in the US is tied to the continuation of practices that expect and demand unpaid or poorly paid dependency work unequally shared between the sexes. When we look globally, we see practices that bind women to caregiving, even when they have traditionally been or are newly propelled into the labor force. Where women are subordinated or exploited, they either are kept from remunerative work and have to be entirely dependent on men for their own and their children's livelihood, are overworked and underpaid because they are taking on productive labor while getting little support for

their caregiving responsibilities, or must choose between their familial dependency relationships and material deprivation for themselves and their families. None of these are good options for women. Considering the gendered nature of carework is a critical factor in any project to develop a global ethics of longterm care.

#### **iv. Societal cultural difference: Gays and Lesbians**

Groups whose oppression is a consequence of cultural practices, gays, lesbians, and transsexuals as well as ethnic and religious minorities have struggles that are less implicated in human dependency. Still, gays and lesbians have fought for recognition of their rights to retain their children, adopt children, take their rightful place by their lover's bedside in hospitals, make decisions about their lovers' medical treatment, that is, issues of dependency care have been central in their demands for recognition. I submit that the victories gays and lesbians have achieved (if they are victories, and I think they are) in marriage rights in the United States are in part a result of their more visible parenting. Permitting gays and lesbians to adopt children and retain their children in cases of divorce has forced a heterosexist society to acknowledge homosexual couples as genuine families, and so deserving of the protections of legal marriage. A global ethics of longterm care needs resources to affirm variant family forms in which caring takes place. This is needed so that those who do the labor of longterm familial caring are not shut out of institutional protections and supports, and so that caring relationships, even when they do not conform to standard norms of family, are respected and preserved.

#### **iv. Societal cultural difference: Ethnic, cultural and religious**

Struggles engaged by those who are religious and ethnic minorities are frequently ones that also involve issues around dependency. They include acknowledging diverse methods of childraising, the rights of the children under different cultural norms, different attitudes to medicine, healing practices, and death and dying. Ann Fadiman's remarkable *The Spirit Catches You and You Fall Down*<sup>xvi</sup> documents the tragic consequences of cultural misunderstandings and arrogance in the longterm care in the treatment of a Hmong child suffering from seizure disorders whose family encounters Western medical treatment. While issues of dependency may not be at the heart of many of the cultural societal inequities, they do constitute a significant aspect of the oppression and domination that these groups experience either as immigrants or as an oppressed ethnic/religious group in their native land. These cultural, ethnic and religious differences surrounding dependency care are also of great importance if an ethic of longterm care is truly to be global and not the imposition of the values of powerful nations. In considering what might constitute a global ethics of longterm care, not only must we consider structural inequalities which lead to the unequal access to goods and the development of human capabilities, but we must also respect the societal cultural differences that inform the care of dependents, as long as these differences are variant ways of promoting, not impeding, the human flourishing of dependents and their caregivers.

## **Part 2: Toward a Global Perspective on the Ethics of Long-term Care: The Practical Problems and Theoretical Issue**

The questions of justice raised by dependency and difference are in danger of being overwhelmed by global looming crisis in long-term care, as expediency and efficiency fill the void left by the failure to set in motion practices that promote justice. How should we think of such practices and how should formulate the needed principles?

It is important to see that issues of justice and ethical conduct are relevant at two levels: the level of public policy and the level of the practical relationships of care-giving. Let us take these in reverse order. First, at the policy and systemic level: We should consider whether long-term care giving (and the meeting of human long term care needs) ought to be seen as a matter of *basic human rights*, and whether the international community ought to include long term care within its human rights conventions and protocols. Here we must speak of both the right to be cared for and the right to care. Are there basic standards and requirements that all nations and societies should meet in the provision of an effective, sustainable long term care system? As ought implies can, *could* such standards apply not only to rich nations, but to poor nations as well? How can we incorporate different cultural and religious understandings of health, illness, care, the role of women, alternate family forms in creating standards for different states?

Second, at the level of human relationships and professional practices: We should ask how caring is best understood ethically and culturally. Are there universal aspects of the meaning and experience of caring, and how can those best be expressed? In a paradigmatic sense, all caregiving involves a direct, intimate relationship between two or more people. All caregiving occurs in a psychological and social context that has shaped, and shapes the experiences of the participants in the caring practice. All caring, therefore, is at once intensely personal and inextricably social, symbolic, and meaningful. It is both deeply emotional and a rational, pragmatic, and practical endeavor. It is a practice that comprises certain fundamental moral virtues and human goods. It can be done well or badly; in a way that enriches or alienates, dignifies or humiliates either caregiver or the one cared for. Above all, caring is a practice that effects both the person receiving care and those providing it, the ethics of caregiving pertain to carer and care recipient alike, and caring brings into being (or rests on) a relationship that has crucial cultural and ethical meanings.

In spite of these commonalities, differences in social traditions, family systems, gender roles, and cultural worldviews affect the understanding of the ethical concerns in relationships of care and the institutional forms through which care finds expression. Contestations around these meanings and practices will, at times, take the form of either mandating that woman stay at home to do carework or questioning the role of women in public life. They also are apparent in different understandings of the responsibilities of society or the family or specific family members (e.g. the eldest daughter) toward the elderly and the ill; different attitudes toward women's roles; or in different understandings of illness, as Fadiman's story of the Hmong child reveals. To a Western sensibility seizure activity is a serious disorder that needs to be managed properly. To the Hmong it was an indication that "the spirit" has caught you. It is a sign of distinction, not an illness to be treated, except perhaps when seizure activity becomes too severe. The

Hmong family did not seek the elimination of the seizures, only mitigation sufficient for the child to get on with his life. Had the doctors grasped the meaning the Hmong attached to seizures, they would have been likely to find better means of treating the seizure disorder—one that would satisfy their own sense of what was good medicine, but also one that could be made to resonate with the Hmong beliefs. The cultural misfiring exhibited in the story Fadiman recounts is frequent around matters of pain treatment, approaches to death, meanings of aging, responsibilities of family members, etc. Professional careworkers, such as doctors, nurses and trained health aides, who may come from different cultural backgrounds or outlook than their patients and their families can clash significantly in the prescriptions for adequate long-term care. But long-term care cannot be an isolated matter for the individual needing care. The individual herself is likely to be ill-served when there is a failure to take into consideration the family and the culture.

Cutting across the policy and personal levels are issues of distributive justice. These are questions of how benefits and burdens of caring ought to be shared? If need, dependency, and human dignity are the moral anchors to a human right to receive adequate long-term care, then considerations of gender equity, quality of care, and claims of reciprocity, memory, and respect limit and condition the practical forms that caregiving should take. In setting out the various and proper roles and responsibilities within a long-term care system, what should be the relationship between kin-based and family ties, on the one hand, and, on the other, the more impersonal, layered communities—from neighborhood and church to charitable organizations, NGOs, and eventually the state and international institutions?

In the realm of distributive justice, the relations between rich and poor nations ought to be considered, particularly as the importation of workers to help solve the care crisis of rich nations contributes to a growing care crisis in poor nations. To mitigate the consequences for poor nations that export care labor, we need to ask if the rich nations that import this labor ought not to have policies regulating work requirements and benefits of migrants. For example, might we demand policies enabling migrant workers with dependents to return home on a regular basis, or permit them to bring along dependent children, or entitle them to certain rights such as social security, even after they return to their home country? Should rich countries that import skilled and semi-skilled careworkers such as nurses and home health aides compensate poor countries for the training that they invested in the skilled labor, but of which the “care drain” now has now deprived them? Should we urge taxation policies on transnational corporations that employ the workers who traditionally have been available to do caring labor, so that poor nations can establish and maintain public systems for care?

### **Resources for a global ethics of longterm care**

As we begin the twentieth-first century one salient lesson from past attempts at health policy reform stands out. That lesson is: Before policy reform, structural change, and the reallocation of health care resources can come about an ethical foundation must be laid for doing so in the culture at large. Without this, policy change is mired in special interests, and there is no broader motivation or momentum for change. This needed “ethical foundation” will consist of the moral principles, social goals, and personal aspirations that call upon leadership to direct change and to rebuild existing institutional

arrangements. When the values and the vision supporting reform are not clear—and have not been forged out of a prolonged process of widespread information sharing, problem identification, and public deliberation and dialogue—then the policy will not gain the political support necessary to prevail in a political system more geared to preserving the status quo than to systemic reform.

What resources are available to inquire into such ethical foundations? While some light has been shed on the problems of long-term care within developed health care systems, relatively little has been done to address the impending global crisis in long-term care or to raise the question of appropriate international expectations concerning the ethical standards appropriate to meeting the long-term care needs of individuals and of populations. The World Health Organization has been active in generating studies that are a good start for future work.<sup>xvii</sup> Feminist ethics offers us a way to begin to fill the theoretical gap, although it is not the only possible resource. Human rights may provide another. Martha Nussbaum<sup>xviii</sup>, has argued for the applicability of the capability approach she has developed based on the original formulation by Amartya Sen<sup>xix</sup> and Norman Daniels<sup>xx</sup> has made the case for adopting a Rawlsian framework to consider the distributive problems in the allocation of resources for providing longterm care. There is a need to explore and clarify the basic ethical and conceptual paradigms that are available in the international community today for framing and guiding long-term care services, systems, and policies. We suggest that there are four such paradigms: (1) the human rights paradigm, and its variant, the capabilities approach; (2) the utilitarian/neoliberal paradigm; (3) the care ethic/feminist ethic paradigm; and (4) the contractarian paradigm.

It is unlikely that only one of these frameworks can do all the conceptual work that needs to be done in long-term care policy; some lead to contradictory and incompatible policy choices; and others can be made to function synergistically to provide a richer, multi-faceted perspective on the ethics of long-term care.

### ***Human rights and capabilities.***

In the last 50 years, a powerful language of human rights has evolved in the international community. Including, but not limited to basic political and civil rights, the human rights paradigm now encompasses access to those social support systems, services, social insurance mechanisms, and educational and employment opportunities that make it possible to pursue a life of freedom and dignity in the world today. Given the importance of caregiving experience in the lives of all individuals, particularly the experience of women in the family and domestic setting, it is interesting that the right to benefit from and to participate in caregiving activities and practices has not heretofore been stressed in the context of those other capacities, freedoms, and opportunities that make up the moral vision at the center of the human rights paradigm. Martha Nussbaum has offered what might be thought of as a variation of the human rights paradigm, the capabilities approach. Nussbaum delineates a relatively short, but broad ranging set of capabilities that reflect “richly human needs.”<sup>xxi</sup> The capabilities should not be understood as realized functionings, for some may not wish to exercise a given capability. A capability, following Amartya Sen<sup>xxii</sup>, gives us the freedom to function, that is, to be permitted or given the capability to exercise a function. These capabilities, she maintains, all need to

be available to individuals for a society to be judged just. In her Tanner Lectures<sup>xxiii</sup>, she maintains that although neither the giving or receiving of care is listed as one of the capabilities, the question of care permeates most all of the listed capabilities. That is to say, for these capabilities to be the capabilities they are, we need to have received or to receive or to be able to give care.

### ***Utilitarian/neoliberal.***

The emerging global political philosophy today seems to be that of neoliberalism. This places an emphasis on free trade and market institutions with minimalist social security and safety net systems financed by nation states in place to prevent abject destitution and suffering for those who do not prosper in the private sector and who have not been able to meet their own needs through market participation, private savings and investment, or through relying on the traditional ethic of care and responsibility within their own family and kinship network. Neoliberalism is an outgrowth of the utilitarian tradition in ethics wherein ethically just policies and social institutions are seen as those which maximize the interests or preferences of the greatest number and minimize disutilities. Although not all utilitarians subscribe to neoliberalism, both base ethics on collective or aggregative benefit, not on the intrinsic moral worth of an individual or on one set of substantive interests or preferences. Both utilitarianism and neoliberalism refuse to define the content of the human good or the set of preferences human beings ought to have. Their focus rather is on designing institutions and social transaction processes that will realize pluralistic conceptions of preference and the human good or flourishing, no matter what they happen to be. Critics maintain that the processes favored by the neoliberals are not in fact morally neutral in that regard but tend tacitly to promote some goods and forms of life over others. Utilitarian approaches that diverge from neoliberalism may well have different contributions to make to the discussion.

### ***Ethic of care/ feminism.***

The ethics of care emerged as a feminist alternative or supplement to theories of justice found in the modern political and moral philosophy. In response to the focus on the individual and the ideals of independence in these theories, an ethics of care emphasizes the relational character of human life, the relational nature of self-conceptions, especially as found in women, and the inevitable human dependences and interdependences that are ignored in theories that begin with adult moral agents who pursue their own conception of the good. An ethics of care takes seriously the labor of care in which women traditionally have been engaged. It argues that the values embedded in this labor, for example, the significance of connection, attentiveness and responsiveness to the need of another, a sense of responsibility for the well-being of another, concern for particular others, are at least as important as justice-based moral conceptions such as rights, impartiality, and autonomy. Critics have argued that the labor of care has been extracted from women in exploitive conditions and thus the values it promotes are suspect as moral values. Yet proponents of an ethic of care have responded that the very possibility of the independence and individualism prized in justice-based moral theories depend on care labor and on some having the values that enable caring to take place. It appears that an ethic of care, and its critiques, will be especially valuable resources in considering a global ethics of longterm care.

### ***Contractarianism***

Contract theory begins with postulating a hypothetical covenant among contracting parties. The parties agree to join together to protect themselves against each other and against outsiders, and to engage in social cooperation so that all fairly share the benefits and burdens of social cooperation. In the version of the contract that John Rawls put forward (which has been immensely influential in contemporary discussions of justice), parties representing citizens in an ideal state, stand behind a “veil of ignorance” that precludes them from knowing their station in life, but allows them needed knowledge of the world and human psychology to formulate principles of justice. Rawls contends that parties behind such a veil would choose two principles of justice: one is an equal opportunity principle that privileges those who are the least well-off (generally known as “the difference principle”), and the other is an equal liberty principle that ensures certain liberties to all. While the social contract tradition is generally viewed as a theory about how societies should be structured, some contractarians have taken the model to be applicable to interpersonal relations. Thus contractarianism may have something to say about issues of distributive justice dealing with care, when viewed as a political theory, and applicability to interpersonal relations between caregiver and cared for when viewed as a theory about interpersonal ethics. A strength of the contractarian model lies in its commitment to the equality and equal freedom of the parties to the original position (that is, the original bargaining position). Another is its impartiality, its adherence to principle, and its commitment to autonomy. But each of these strengths can also be a weakness when considering situations of care. Situations of care are not between persons who are equally situated or equally empowered. Those cared for are frequently not able to be autonomous and many times caregivers do not freely engage in caregiving but have it

thrust upon them by circumstance or convention. Situations of care frequently do not lend themselves to abstractly formulated principles and caring activity generally implies favoring some interests over others and thus not acting impartially. Furthermore, contractarians generally have little to say about the inevitable human dependencies to which caregiving is a response, including such basics as healthcare. At least one contractarian has argued that by including issues of health, including longterm care, as a matter of equality of opportunity, issues of care, particularly those that are questions of distributive justice, can be treated on a contractarian model.<sup>xxiv</sup>

### **The Global Context Of Ethical Paradigms**

It is critical to place each of these paradigms in a cultural, social, and ultimately a global context. Only in this way—as philosophical ethics comes into dialogue with cultural and ethnic traditions and belief systems—will it be feasible to fashion the kind of discourse that will resonate in the coming years in international dialogue and debate. In speaking of the African context, Dan O. C. Kaseje and Bavon Mpenda<sup>xxv</sup> express an example of considerations that must come into play. They speak of the need to provide long-term care “in a way that promotes the African culture of solidarity and respects the sanctity of life.”<sup>xxvi</sup> They speak of the need to moderate the principle of autonomy in order to respect the communal nature of African society, and they stress the communal aspect of the allocation of resources in the case of “the harsh African context [where] access to scarce services may be linked to the survival of a people.”<sup>xxvii</sup> In this context, they urge, the consideration must be to the well-being of the community as a whole rather than to its individual members.

At the same time, we need to ask if accommodating to these harsh conditions should be encoded in *principles* or if *principles* should rather provide standards to which we ought to aspire (sometimes spoken of as *ideal* theory), even knowing that real conditions are far from ideal and accommodations must be made in the face of current injustices.

This last point goes to the heart of the inquiry. We need a vocabulary for expressing the membership and value of those persons who cannot be self-reliant, autonomous, or productive in the ways that are commonly valued within rich Western nations and in ways that poor struggling populations sometimes require for survival. We in developed rich nations need a vocabulary that has a stronger emphasis on interdependency, mutual assistance, relationships and commitments built up over time, solidarity, gratitude, human dignity, and respect—values which are in danger of eroding as the competition for wealth becomes more rabid. People in the developing, poor nations need ways of coping with a care crisis that threatens to challenge and disrupt the forms of interdependency and community that have characterized the lives of many, so that the ethical fabric of their lives does not unravel and so they have tools for making demands of those who have the power to help with solutions. We all need to find alliances that will help redefine our values, and bring new values into our relationships and our public policy.

### **Part 3: Building Alliances to Face the Crises of Care**

Exploring the role of care and dependency in a politics of difference with regard to formulating a globally efficacious ethical foundation for longterm care reveals that we ought not to speak of *the* crisis of care or *the* crisis of longterm care but of the *crises* of care. In longterm care, we observe that there is not only a crisis for those needing the

care, but also a crisis for those caregivers who will be called on to respond. The first crisis threatens the vulnerable with the prospect that their needs will not be filled. The second crisis threatens those called on to provide the care with exploitation and exhaustion. The crisis of longterm care for wealthy nations is interconnected but different from the one faced by poor and developing nations. Wealthy nations confront the confluence of improved medical care leading to greater longevity and increased control over fertility, which means fewer people are born to care for the growing numbers of elderly. These nations have the resources to import caregivers from poor nations to help mitigate their care deficit. The crisis for poor nations who lose their traditional caregivers is confounded by a lack of resources for the most basic care along with the economic effects of globalization and the disruptions development poses to traditional arrangements for caring.

When we acknowledge not only our global interdependence, but the inevitable dependencies of our species being, we bring to light our human commonalities. Saying that there is a global crisis of care that requires a multifaceted approach that is international in scope suggests that this is a basis for new alliances to solve a problem that will soon confront us all. But as a politics of difference has taught us, a facile focus on commonality or sameness, one which masks genuine conflicts of interests, has the effect of benefiting most those who are already most privileged. What we must take from a politics of difference is that alliances are only possible when we first acknowledge how our differences lead to conflicting interests even when the problem we need to solve appears to be the same problem. In the case at hand, a crisis in longterm caregiving, we must understand how our interests collide and seek solutions that are just for all. That is, we cannot think about issues of care, care ethics, the demands on caregivers, the needs of the cared for without also thinking about who in fact does the care, how the labor of caring for dependents can and should be reorganized, how injustices and the impending crisis of longterm care are, in part, a consequence of current social technologies designed to care for dependents. Nor can we think about these without examining the question of how we look at, treat, incorporate or exclude those who are dependent.

This means an uneasy alliance between those women in the corridors of Partners of Care, and the people sitting in the conference room. It means an uneasy alliance between those who wash and change the nappies of our children and our aging parents, who assist the disabled person eager to be productive and independent, and those of us who have a disabled dependent person for whose well-being she is responsible. And the alliance is uneasy because those who have the need for dependency care or the responsibility for dependents (but do not want or cannot do that work), are wary of how much (whether paid out directly or indirectly through state taxes) they are willing (or able to) part with for the sake of good care for dependents. The strike that brought the home-health aides of New York City improved wages will, I believe, eventually translate into better care for their clients, but not a few elderly suffered the lack of services during the duration of the strike, and the well-deserved improved wages will come out of someone's pocket. The alliances are also difficult because gender practices around dependency care continue to be deeply engrained in practices imbued with culturally potent, gendered, and often religious meanings.

And finally alliances are difficult because owning up to our own dependency and vulnerability is difficult.

This last point is, I believe, at the crux of the difficulties and is, to an important extent the reason why we have prepared ourselves so poorly for the immanent problems of longterm care. The point is perhaps best illustrated through the example of disabled persons who require person assistants and those who are paid to assist them.

An important feature of the disability rights movement that emerged in the early 1970's was the demand for "independence." The shining star of the movement was called the "Independent Living Movement." The idea behind this movement was that dependency of disabled people was socially constructed. People with impairments become disabled not by virtue of the intrinsic nature of the impairment, but because of physical and social constructions that become a barrier to living independent lives. Yes, the activists and theoreticians of the movement concede, many people with impairments need assistance, but this does not constitute dependence. With that assistance and control over the aid they receive, persons with impairments can live "independent" lives.

In cultures where independence is the indispensable ticket to full citizenship and full social participation, this rhetoric is certainly of great use. But it is premised on the invisibility of she who provides the assistance. Lynn May Rivas, a researcher delving into the experiences of disabled people and personal assistants, describes an encounter with one of her subjects, a disabled man who does not have use of his hands. During the interview he is getting dehydrated and very much needs a sip of water. He calls for his personal assistant, who has gone outside to allow him and his interviewer privacy. In his view, Rivas surmises, he refuses assistance she offer because accepting her help renders him a suppliant, indebted to *her willingness* to help. In contrast, he maintains his independence when he receives the water from the personal assistant—who merely serves as the instrument of *his own* will.

Rivas, the daughter of a Mexican immigrant mother who worked as a personal assistant and had to choose between taking care of her client and her own ailing mother, had herself worked as a personal assistant. Rivas herself stepped in to help her mother by caring for the client allowing her mother to care for her grandmother. It was not only financial pressure, but also a sense of responsibility and sensitivity to her client's real needs that held her mother in her job, and Rivas took over the job to help her mother in turn. Rivas, then, has had multiple perspectives on the matter she is researching.

Of special interest to her is the importance of the invisibility of the careworker. The disabled person needs the assistant to be invisible in order to maintain a sense of his independence, and sees the relationship as best achieved when entirely professional. The assistant also understands the importance of her own invisibility. A good careworker, I have argued elsewhere, must make herself transparent to the needs of the person who depends on her. She must not interject her own desires, aspirations or wishes and so distort or fail to perceive the need she is there to meet. This transparency, or invisibility as Rivas would have it, is an achievement on the part of the careworker. It is part of doing a being a good caregiver, something achieved by attention and love. But Rivas maintains, the invisibility comes at a terrible cost for the careworker, for while she takes it as a labor of love, the one she cares for sees it as just part of the job description. It also involves what Rivas refers to as a transfer of authorship and this too comes at a great cost to the careworker. To be invisible and to transfer authorship, says Rivas, "is the first step toward being considered nonhuman...invisibility is...the ultimate manifestation of self-estrangement."<sup>xxviii</sup> And, though the disabled people she interviewed indicated that what

they sought and valued in personal assistants was their invisibility, Rivas asks with good reason, “How could something unseen be completely valued?”<sup>xxix</sup>

Here we have a quintessential ethical dilemma of caregiving. Two populations, disabled people and prototypical caregivers (a person of color and/or female and/or poor and/or an immigrant) each experiencing discrimination and oppression and each have legitimate claims to recognition of who they are and what they need to live flourishing lives. Both have much to gain from the relationship. But the caregiver who asserts herself and refuses to be invisible fails to provide what the disabled person needs, and the disabled person who wants an invisible caregiver, is unlikely to be able to see the caregiver’s full humanity and value her accordingly. How can such conflicts of interests be reconciled? Perhaps they cannot where independent is valorized and dependency is stigmatized. Perhaps they cannot where the supports are not in place to give the caregiver the recognition she requires to be apprehended in her full humanity.

I propose that if instead of demanding an independence for all that can only be maintained by denying the reality of our connection to and reliance on others, we give acknowledge our own dependency and vulnerability, we do not need to make the caregiver invisible. We may still require the transparency of self needed for a careworker to meet the needs of the one she cares for. Yet if she too is recognized as one needing and deserving care, such transparency only need mean a deferment of her own wishes and desires, not their obliteration. The recognition requires social structures and an ethical framework are needed. Although a complete global ethics of longterm care may need to deploy many theoretical resources, for starters I want to offer the notion I introduced at the start of this paper, that “we are all some mothers’ child.” This adage is intended to carry metaphorically both the understanding of our inherent dependency and the need to honor the needs arising from that dependency not only in the one whose needs are most urgent at the moment, but also in the one who meets those needs.

As a vision of the independent agent has long informed theories of justice and flourishing, how can we reimagine what it means to be dependent or to have to do the work of attending to dependency needs? I suggest that we consider how to fashion a conception of justice that provides us with social structures that will allow the extent and severity of our dependency needs to be rendered indifferent to our capacity to flourish. Additionally, we should see how meeting our dependency needs can and does offer us an opportunity for flourishing.

Can we think of a need as anything other than a barrier to well-being, something to overcome or satisfied as a means of moving on to better things? I invite the reader to consider, by way of analogy, the need for food in order to see how needs are themselves not merely something to overcome, but that satisfying these needs can become an occasion for flourishing.

We already seek justice that makes the satisfaction of hunger a requirement of justice. We view differences in need for food as irrelevant to the need to have hunger satisfied. Similarly, we view it as an injustice when farmers who grow our food are poorly remunerated. We understand the justice of hired hands who strike for better wages. Similarly, whether our dependency needs are minimal or significant ought to be indifferent to our ability to flourish. A just society would meet those needs, however demanding they are, within the constraints of available resources. Meeting those needs means not only making sure the need to be cared for is met, but also that those who provide the care be well treated. This is what I mean when I say that justice should be dependence indifferent.

But what about the second notion, that dependency be seen as offering an opportunity for flourishing. Again consider our need for food. At times, we compete bitterly for food. But we also cooperate in obtaining and preparing food, and in that cooperation, not only do we satisfy our hunger, but we forge alliances, friendships, and the foundations for social organization. Furthermore food is not only something that satisfies our hunger. Food prepared with interest, artistry, and love becomes the source of refined pleasures, creativity, and sociality. Food in intimate settings becomes a means by which love is shown. Food in larger social settings becomes a form of bonding among social groups. What serves as food for one group does not serve as food for another and that difference is one we can either use as a basis for denigrating others or we can make the difference something to celebrate.

Similarly, our need for care can be, as we have shown, a source of conflict, or it can, does, and should become an occasion for forming deep and abiding bonds of love and friendship. Differences in ways of responding to dependency can be celebrated when met with fairness and kindness. A fair and just organization of care labor can offer the opportunity to create societies in which trust, real fellowship, and real difference can co-exist. Efforts to find new solutions to the demands of caring can offer an opportunity for creativity and inventiveness. Revising social institutions and values to acknowledge our dependency presents the possibility of building the society visionaries have dreamed of, one that recognizes commonality and respects difference.

Only by working through the conflicting interests, recognizing the source of the conflict, looking at presuppositions and assumptions that make the conflicts inevitable, and searching for better understandings that will allow us to envision new ways of meeting the inevitable human need for care, can we hope to form the alliances we will need to meet the crises of longterm care that have begun to confront us all.

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## Notes

<sup>1</sup>In each of the eight regions of the world studied: the Former Socialist Economies of Europe; the Established Market Economies; China; India; Latin America; The Middle Eastern Crescent; Sub-Saharan Africa; and Other Asia and Islands, that is, throughout the globe, the dependency ratios have either risen or are projected to rise by 2050. See "Current and Future Long-Term Care Needs: An Analysis Based on the 1990 WHO Study *the Global Burden of Disease* and the *International Classification of Functioning*,

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*Disability and Health*," (World Health Organization and The Cross-Cluster Initiative on Long-Term Care, 2002), 19..

<sup>ii</sup> The situation is better in the Scandinavian countries, but not much better in the UK, France, and Germany. Outside of Western Europe and North America, little public infrastructure exists for long-term care and the caregiving system is almost entirely comprised of the family and kinship networks.

<sup>iii</sup> It is important to note that not all who are elderly, have chronic illness or significant impairment require the assistance of others in daily care, and many who do, do so only because their ability to engage in self-care is limited by a lack of environmental supports and adaptations. Attention to when care is the appropriate response to a condition and when other forms of support should be put in place are part of the project of determining just and caring ways to deal with longterm care issues.

<sup>iv</sup> The Swedish cooperative of cognitively impaired persons, JAG, utilizes two sorts of caregivers for their members: the "personal assistants" who provide the hands-on care, and the "service guarantors." Service guarantor are chosen by the member to oversee the quality of care provided by the personal assistant and to express problems that the member herself cannot. They very know the client very well, and help to extent the agency of people whose disabilities limit their capacity for agency. But if necessary, the service guarantor will step into the role of personal assistant for theirs is the ultimate responsibility for the care of the JAG member. Sometimes the service guarantor is also the member's personal assistant. Both roles are compensated, even when either occupied by a family member. For more information, see JAG, "The JAG Association," (Stockholm, Sweden: 2004). I believe that employed mothers, and less often fathers, play an analogous role for their children, just as a son or daughter with an ailing parent will do for his or her parent even when they hire paid workers to do daily hands on care, and even though they receive no remuneration for this work. I would maintain that both services are forms of dependency work/care. However, a parent who sees their sole responsibility to be income-earner, (and will not, or has no clue of how to step in when a caregiver does not show up), can hardly be said to be a caregiver, although he does serve as a provider and support for the caregiver.

<sup>v</sup> In the U. S. today, professional care now accounts for twenty per cent of the total paid labor force, according to Nancy Folbre, *The Invisible Heart* (New York: The New Press, 2001), 55.

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<sup>vi</sup> Iris Young, "Structural Injustice and the Politics of Difference" (paper presented at the XI Symposium of International Association of Women Philosophers –(Internationalen Assoziation von Philosophinnen IAPh)--The HUMAN GOOD Dignity – Equality – Diversity, Göteborg, Sweden, June 17-19, 2004 2004)..

<sup>vii</sup> In Iris Marion Young, *Justice and the Politics of Difference* (Princeton, N.J.: Princeton University Press, 1990).

<sup>viii</sup> See Dorothy E. Roberts, "Poverty, Race, and the Distortion of Dependency," in *The Subject of Care*, ed. Eva Feder Kittay and Ellen K. Feder (Totowa, New Jersey: Rowman and Littlefield, 2002).

<sup>ix</sup> In Rhacel Salazar Parrenas, *Servants of Globalization: Women, Migration and Domestic Work* (Stanford, CA: Stanford University Press, 2001).

<sup>x</sup> Eva Feder Kittay, *Love's Labor: Essays on Women, Dependency and Equality* (New York and London: Routledge, 1999).

<sup>xi</sup> Barbara Ehrenreich and Arlie Russell Hochschild, ed., *Global Women: Nannies, Maid and Sex Workers in the New Economy* (New York: Henry Holt and Company, 2002)..

<sup>xii</sup> Arlie Russell Hochschild, "Love and Gold," in *Global Women: Nannies, Maids and Sex Workers in the Global Economy*, ed. Arlie Russell Hochschild (New York, New York: Henry Holt and Company, 2002)..

<sup>xiii</sup> Celia W. Dugger, "An Exodus of African Nurses Puts Infants and the Ill in Peril," *New York Times*, July 12, 2004 2004. See also Health Systems Resource Centre Department for International Development (DFID), *International Recruitment of Health Workers to the UK: A Report for DFID* (2004 [cited]); available from [http://www.dfidhealthrc.org/Shared/publications/reports/int\\_rec/int-rec-main.pdf](http://www.dfidhealthrc.org/Shared/publications/reports/int_rec/int-rec-main.pdf) [http://www.dfidhealthrc.org/Shared/publications/reports/int\\_rec/exec-sum.pdf](http://www.dfidhealthrc.org/Shared/publications/reports/int_rec/exec-sum.pdf).

<sup>xiv</sup> United Nations Development Program, 1999, 3, cf. 38. Also cited in Hochschild, "Love and Gold," 17.

<sup>xv</sup> Ofelia Schutte, "Dependency Work, Women, and the Global Economy," in *The Subject of Care*, ed. Eva Feder Kittay and Ellen K. Feder (Totowa, New Jersey: Rowman and Littlefield, 2002).

<sup>xvi</sup> Anne Fadiman, *The Spirit Catches You and You Fall Down : A Hmong Child, Her American Doctors, and the Collision of Two Cultures*, 1st ed. (New York: Farrar Straus and Giroux, 1997).

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<sup>xvii</sup> See the following studies: "Current and Future Long-Term Care Needs: An Analysis Based on the 1990 WHO Study *the Global Burden of Disease* and the *International Classification of Functioning, Disability and Health*,"; J. Habib J. Brodsky, M. Hirschfeld, ed., *Key Policy Issues in Long-Term Care* (Geneva: WHO and The Cross-Cluster Initiative on Long-Term Care, The WHO Collaborating Center for Research on Health of the Elderly JDC-Brookdale Institute, 2003); WHO, "Ethical Choices in Long-Term Care: What Does Justice Require," (Geneva: World Health Organization, 2002); and The Cross-Cluster Initiative on Long-Term Care WHO, "Lessons for Long-Term Care Policy," (Noncommunicable Diseases and Mental Health Cluster, World Health Organization, The WHO Collaborating Centre for Research on the Health of the Elderly, JDC-Brookdale Institute, 2002)

<sup>xviii</sup> See Martha Nussbaum, *Beyond the Social Contract: Toward Global Justice, The Tanner Lectures in Human Values 2002* (Cambridge, MA: Harvard University Press, 2002); Martha Nussbaum, "'Long-Term Care and Social Justice: A Challenge to Conventional Ideas of the Social Contract' (Appendix A.) in *Ethical Choices in Long-Term Care: What Does Justice Require*," (Geneva: World Health Organization, 2002)

<sup>xix</sup> Amartya Sen, "Equality of What?," in *Welfare and Measurement*, ed. Amartya Sen (Oxford: Basil Blackwell, 1982).

<sup>xx</sup> Norman Daniels, "'Need We Abandon Social Contract Theory? A Reply to Nussbaum' (Appendix B). In *Ethical Choices in Long-Term Care: What Does Justice Require*," (Geneva: World Health Organization, 2002); Norman Daniels, *Am I My Parents' Keeper? : An Essay on Justice between the Young and the Old* (New York: Oxford University Press, 1988); Norman Daniels and James E. Sabin, *Setting Limits Fairly : Can We Learn to Share Medical Resources?* (Oxford ; New York: Oxford University Press, 2002).

<sup>xxi</sup> Nussbaum, "'Long-Term Care and Social Justice: A Challenge to Conventional Ideas of the Social Contract' (Appendix A.) in *Ethical Choices in Long-Term Care: What Does Justice Require*,"

<sup>xxii</sup> Sen, "Equality of What?."

<sup>xxiii</sup> Nussbaum, *Beyond the Social Contract: Toward Global Justice*.

<sup>xxiv</sup> See Daniels, *Am I My Parents' Keeper? : An Essay on Justice between the Young and the Old*; Daniels, "'Need We Abandon Social Contract Theory? A Reply to Nussbaum' (Appendix B). In *Ethical*

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*Choices in Long-Term Care: What Does Justice Require,*"; Daniels and Sabin, *Setting Limits Fairly : Can We Learn to Share Medical Resources?*

<sup>xxv</sup> Dan O. C. and Bavon Mpenda Kaseje, "The African Perspective," (Geneva: World Health Organization, 2002)

<sup>xxvi</sup> Ibid., 87..

<sup>xxvii</sup> Ibid., 88.

<sup>xxviii</sup> Lynn May Rivas, "Invisible Labors: Caring for the Independent Person," in *Global Women: Nannies, Maids and Sex Workers in the Global Economy*, ed. Barbara Ehrenreich and Arlie Russell Hochschild (New York, New York: Henry Holt and Company, 2002), 79.

<sup>xxix</sup> Ibid., 80..