

Dependency, Difference and the Global Ethic of Longterm Care*

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I. INTRODUCTION: DEPENDENCY AS THE “ELEPHANT IN THE ROOM”

PEOPLE do not spring up from the soil like mushrooms. People produce people. People need to be cared for and nurtured throughout their lives by other people, at some times more urgently and more completely than at other times. Who is available to do the labor of care and who gets the care they require is contingent on political and social organization. Similarly, norms surrounding both the giving and receiving of care, while dictated in part by the nature of human need, is also conditioned by cultural and ethical understandings and by economic and political circumstances. The distribution of care therefore is a question of justice and the interactions between carer, cared for, and the larger community an appropriate matter of ethical inquiry. Demographic alterations due to birth and mortality rates, migration, and employment opportunities (and expectations) can have a profound impact on the availability and quality of care, and on the distributive questions of who does the caring and who gets care. Furthermore these demographic shifts affect the provision of care on a global level, when those who can pay for care buy the services of careworkers in other parts of the world.

Care and dependency, particularly in the form of dependency care have been, are, or are likely to be features of all our lives. By “care,” in the context of this article, 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

*Much of the first half of the essay was based on the writing of and discussions with Bruce Jennings and Angela Wasunna. I would like to thank Robert Goodin for his illuminating substantive comments and useful editorial suggestions.

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. 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.¹

There appear to be universal aspects of the meaning and experience of caring. 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.

However, differences in ability, race, gender, sexuality, religion, culture, and geography orient us differently towards “inevitable dependencies,” making

¹The 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 guarantors 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 know the client very well, and help to extend 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 is 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.

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,² 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.³

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 carer 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.

In what follows, I explore a number of issues that demand the attention of all those interested in questions of care (and especially the longterm care of the

²In the US today, professional care now accounts for twenty per cent of the total paid labor force, according to Nancy Folbre, *The Invisible Heart* (New York: New Press, 2001), p. 55.

³An early statement of this point is found in Robert Paul Wolff, “There’s nobody here but us persons,” *Women & Philosophy*, ed. Carol C. Gould and Marx W. Wartofsky (New York: Putnam, 1980), pp. 128–44. The point has been repeated and elaborated in the work of philosophers who work in the “ethics of care.” See for example: Annette C. Baier, “The need for more than justice,” *Justice and Care*, ed. Virginia Held (Boulder, Colo.: Westview Press, 1995), pp. 47–58; Seyla Benhabib, “The generalized and the concrete other,” *Women and Moral Theory*, ed. Eva F. Kittay and Diane T. Meyers (Totowa, N.J.: Rowman and Littlefield, 1987), pp. 154–77; and Virginia Held, “Non-contractual society: a feminist view,” *Canadian Journal of Philosophy*, Supplementary vol. 13 (1987), 111–35.

frail elderly, the chronically ill and disabled), and of justice, locally and globally. I draw few conclusions, arguing instead for the urgent need to formulate a globally pertinent ethics of longterm care. Once I comment on the need to look at care which is long-term and the importance of considering the issues globally, I explore the importance of dependency concerns to those who are disadvantaged or oppressed by a “politics of sameness,” that is to say, 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.⁴ 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 who 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.

I claim that only by forming alliances between parties who have similar needs can we begin to find ethical resolutions to an impending crisis of longterm care. But while the different groups that need to be allied have similar needs, they also have conflicting interests. I claim that only by attending to the differences and conflicts can we begin to find a way to attend to the universal import of human dependency, and so to approach a global ethics of care. In particular, I believe that only by a reevaluation of dependency can we find the resolve to face the looming need for longterm care. I conclude with a vision of how dependency needs might be understood so that together we can work to establish more caring and just systems of meeting these needs.

II. WHY LONGTERM CARE? WHY GLOBAL?

A. AN ANECDOTE

I begin our considerations with an image retained from a recent conference I attended entitled “Rethinking dependency in a medical context.” The scene was one of home health aid workers who had gone on strike for improved wages, and who, in the immediate aftermath of a partially successful strike, were amassed in the same building as the conference in question. The halls of Partners for Care, the agency hosting the conference and employer of these women, were filled with women who, speaking in an English inflected with a Caribbean accent, praised the “mighty God” and “on-time God” they served for bringing the strike to a speedy end.

The women seemed to be cut of one cloth: all aged between twenty and fifty, all women of color, black or brown, with a sprinkling of Latinas and Asian women. The conference participants were equally homogeneous, mostly white,

⁴See for example, Iris Marion Young, *Inclusion & Democracy* (Oxford: Oxford University Press, 2000).

middle-class with advanced educational degrees. The women outside were engaged in exactly the work the people at the conference were discussing. As the conferees pondered how to improve the conditions under which people received and gave long-term care, these women had undertaken action to bring about some of the needed improvements, better pay and health benefits. These women had done what seemed unthinkable and, in their native lands, may well have been inconceivable. They had walked out on their dependent charges, mostly frail and ailing elderly folks, and insisted on what was their rightful due, a living wage.

The contrast between conference members and the women in the halls bespoke a familiar division of labor found 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 typify that 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.

The longterm care these women provide is as importantly intertwined with issues of childcare as are the domestic and global aspects of caregiving. 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.

B. LONGTERM CARE

We tend to think of the production of people in terms of children and child-care. But long-term care is fast becoming an issue at least as pressing now and will only be more so in the years ahead. The importance of the issue of longterm care hardly requires elaborate discussion. In the United States alone, demographics 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.” The dependency ratio indicates the economic dependency of those who are presumed to be beyond their productive years on those who are in the workforce. It can be used to provide a standardized measure by which to assess the demand by those who will be likely to require dependency care on those who are available, either professionally or informally,

to provide it. In each of the eight regions of the world studied by the WHO:⁵ 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 2050.⁶ China will, by some estimates, have one person requiring daily help for every five persons who are employed. 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 chronic fiscal problems, the crisis is, in fact, already upon us.⁷

The dependency ratio, we should note, does not differentiate between older persons who need dependency care and those who do not, and so it may well overstate the requirements for dependency care if taken as an indicator of such needs. Furthermore it employs the unquestioned and misleading assumption that the class of individuals dependent on care does not overlap with the class comprised of the working population. Still, the increase in dependency ratios worldwide is suggestive of the increasing need for longterm assistance of older persons and the diminishing numbers of younger people who can both provide economically and be available to care for the frail elderly.

It is also important to note that many elderly (as well as many younger disabled people) who do find themselves dependent do so only because their ability to engage in self-care is limited by a lack of environmental supports and adaptations.⁸ 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. This means that finding ethical resolutions to the problem of longterm care is not always limited to provision of care *per se*. In this regard as in several others, longterm

⁵See "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*," (Geneva: World Health Organization and The Cross-Cluster Initiative on Long-Term Care, 2002), p. 19. Available at http://www.who.int/chronic_conditions/en/ltc_needs.pdf.

⁶In the study cited in the previous note, 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 are offset in large increases in its dependent population.

⁷Relevant demographics in the United States chronicle the changes in age distribution from 1980 to 2000. While in 1980 the single largest population segment was between ages 20–30, in 1990 it moved to between 35–45, and in 2000 it shifted upward to between 40–50. During that same period, the number of people 80 years old doubled. It is evident that the aging of the US population will result in increasing problems with longterm care for the elderly. The situation is better in the Scandinavian countries, but not much better in the UK, France, and Germany. Outside of Western Europe, Australia, New Zealand 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. See Roy Amara et al., *Looking Ahead at American Health Care* (McGraw Hill Health Professions: 1988).

⁸I am indebted to discussions with Rosemary Quigley and Anita Silvers for the notion of a self-carer—that is a person whose disabilities require care that, under the right circumstance and with the right support, one is able to administer to oneself. These forms of caregiving include the self-injection of medications, self-monitoring of fragile health conditions, dealing with crucial adaptive equipment maintenance and repair, etc. It also includes engaging in the activities of daily living with the assistance of adaptive devices—without which the person would be dependent on another for care.

care traverses the area of welfare and healthcare. Here healthcare is a clinical matter and as a matter of public health and public accommodations for disability.

Longterm care as well as childcare have traditionally been provided within the family. But because parents and family members now live much longer than in times when families could cope with the care of the elderly, because globalization has disrupted many traditional forms of caregiving arrangements, and because so many women are now in the paid workforce, obligations of familial caregivers increasingly need to be supplemented by non-familial caring. Paid caregivers and professionals must do a growing proportion of caregiving, presenting the problem of where to find employable careworkers and the funds to pay for them. When not privately funded (and this is rare since long-term care can become very costly even when paying careworkers relatively little), the funding for carework is provided by the state, NGO's, religious and charitable institutions or through workplace benefits. Welfare states have confronted some of these issues, but they have done so only by thinking in domestic terms. Yet the thinking needs to expand beyond national borders, for as Barbara Ehrenreich and Arlene Hochschild have argued, the solution to the care crisis in wealthy nations is giving rise to a crisis of care in the poor nations.⁹

C. A GLOBAL PERSPECTIVE

As caregiving and caregivers cross national boundaries, issues of longterm care give rise to questions of distributive justice that cross these boundaries. So, the claim that the importation of workers to help solve the care crisis of rich nations contributes to a growing care crisis in poor nations forces us to consider possible forms of redress. Even if there is not a direct causal link between the importation of care workers into wealthy parts of the world and a care crisis in the developing world, we may well want to ask if the wealthy nations do not have an ethical obligation to mitigate the hardship of poor nations facing problems of longterm care. Meeting such an obligation would involve policies directed at individual caregivers, the families left behind, and the poorer nations that face crises in care. To aid the individual caregivers and their families, we might say that the rich nations that import this labor should regulate work requirements and provide benefits to migrants. For example, policies that enable migrant workers with dependents to return home on a regular basis, or immigration policies that permit care workers to bring along dependent children, or benefit programs that entitle them to retain rights such as social security even after they return to their home country would greatly improve the lot of migrant care workers.

⁹Barbara Ehrenreich and Arlie Russell Hochschild, ed., *Global Women: Nannies, Maid and Sex Workers in the New Economy* (New York: Holt, 2002).

Nation to nation obligations may include the demand that rich countries which import skilled careworkers such as nurses, medical technicians, and doctors compensate poor countries for their investment in training skilled labor withdrawn by the “care drain.” Policies may be needed to regulate the workings of transnational non-governmental institutions, such as transnational corporations. When operating in poor nations, these corporations profit from the comparably low wages they can pay these workers. But these are often women who traditionally have been available to do caring labor. As they enter the labor force and earn a wage, they become unavailable for carework. One could argue for the need for international regulations that protect workers and their families by ensuring some time for carework, not only for children but for elderly or disabled family members as well. One may want to insist that these corporations exploit human resources, just as international corporations have traditionally exploited other natural resources, and as they are frequently taxed for the exploitation of natural resources, so they ought to be taxed for the utilization of human resources. These are taxes that could then be used to fund childcare, eldercare or other longterm care arrangements.

As we contemplate the demographic shifts in the ages of populations worldwide, and add to these the changing role of women, the transnational and rural-to-urban migrations of care workers, the AIDS pandemic and armed conflicts, we see that the question is not whether, but how, current systems will have to change in order to meet the need. 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 valued.

III. RESOURCES FOR A GLOBAL ETHICS OF LONGTERM CARE

A salient lesson from past attempts at health policy reform is that 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.

What ethical resources will allow us to appreciate human dependency, value caring, and provide the basis for fair cooperation around issues of longterm care among people who occupy different social positions, both domestically and globally? What ethical resources will help bridge the different interests of people, whose divisions along lines of class, gender, race, cultures, ethnicities and nationalities situate them differently with respect to care, even as they share the

need to give and receive care that preserves human dignity and human relationships. A number of ethical frameworks have been employed in dealing with health care issues, but few have dealt successfully with issues of care per se, and especially longterm care.¹⁰ I suggest that there are five such paradigms: (1) the human rights paradigm;¹¹ (2) the contractarian paradigm;¹² (3) the utilitarian/neoliberal paradigm;¹³ (4) the capabilities approach; and (5) the care

¹⁰The World Health Organization has been active in generating studies that are a good start for future work. See the following studies: "Current and future long-term care needs"; J. Habib, J. Brodsky, M. Hirschfeld, eds, *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) available at http://www.who.int/chronic_conditions/en/Policy_Issues.pdf; WHO, *Ethical Choices in Long-Term Care: What Does Justice Require* (Geneva: World Health Organization, 2002) available at http://www.who.int/chronic_conditions/en/ethical_choices.pdf; 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) available at http://www.who.int/chronic_conditions/en/ltc_policy_lessons.pdf.

¹¹In the last 50 years, a powerful language of human rights has evolved in the international community. 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. However, the notion of "rights," as in client rights, user rights or patient's rights has been employed in protecting the autonomy and interests of some vulnerable populations. (I thank Robert Goodin for pointing this out to me.) While the rights language has important rhetorical and strategic importance, when the populations at issue are especially vulnerable and dependent, the practical utility of such rights are questionable. (For an excellent discussion of this point see Diane Gibson, "User rights and the frail aged." *Journal of Applied Philosophy*, 12 (1995), 1–11.

¹²Elsewhere I argue that even John Rawls' contemporary version of the contract fails to incorporate the fact of human dependency and that because he does not attend to it, the contractual situation Rawls envisions fails to assure *both* that those who need care will be cared for *and* that those who do care will not be exploited by the rest of the population (who effectively freeloan on those who take on that responsibility). See Eva Feder Kittay, "Human dependency and Rawlsian equality," *Feminists Rethink the Self*, ed. Diana T. Meyers (Boulder, Colo.: Westview Press, 1997), pp. 219–66. The contractarian model might seem attractive for dealing with issues of care, for with its commitment to equality, impartiality, and autonomy it helps to reestablish an equality, sense of fairness and respect for choice rarely accorded to those who are dependent. Yet care rarely takes place between persons who are equally situated or equally empowered, partiality is generally appropriate in situations of care, and autonomy can only be very imperfectly realized for those who are highly dependent and in a very vulnerable situation. One influential contractarian, Norman Daniels, 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. See Norman Daniels, *Am I My Parents' Keeper?* (New York: Oxford University Press, 1988); Daniels and James E. Sabin. *Setting Limits Fairly: Can We Learn to Share Medical Resources?* (New York: Oxford University Press, 2002); and Daniels, "Appendix B: Need we abandon social contract theory? A reply to Nussbaum," *Ethical Choices in Long-Term Care*, pp. 67–75. But in the same volume also see Martha Nussbaum, "Appendix A: Long-term care and social justice: a challenge to conventional ideas of the social contract," pp. 31–65 and Eva Feder Kittay, "Appendix C: Can contractualism justify state-supported long-term policies?" pp. 77–83 for a critique of the contractarian tradition.

¹³The emerging global political philosophy of neoliberalism places an emphasis on free trade and market institutions with minimalist social security and safety net systems. But markets and free trade are not care-friendly. Carework has not been well served by market forces. For example, the migrations that deplete home nations of careworkers are importantly a consequence of globalization. Furthermore the effects of "commodifying care" are often not salutary. See Paula England and Nancy

ethic/feminist ethic paradigm. It is unlikely that only one framework can do all the conceptual work that needs to be done in long-term care policy. But for the purposes of this article, I focus briefly on the capabilities approach and more extensively on a care ethics. These I believe prove most relevant to concerns of dependency, care, and difference.¹⁴

A. THE CAPABILITIES APPROACH

Martha Nussbaum, whose work on capabilities draws on that of Amartya Sen,¹⁵ delineates a relatively short, but broad ranging set of capabilities that reflect “richly human needs.” In her *Tanner Lectures*, she maintains that although neither the giving or receiving of care is listed as one of the capabilities, the question of care permeates almost all of the listed capabilities.¹⁶ There she also highlights justice to people with disabilities, particularly cognitive disabilities, offering a litmus test for the adequacy of theories of justice—a test, she argues, the capabilities approach passes. The capabilities approach to justice and ethical relations in global care situations may be more directly applicable than some of the other approaches, especially as Nussbaum and Sen have offered capabilities as a measure for interpersonal comparisons of well-being that may be useful for cross-cultural assessments.

Folbre, “Contracting for care,” *Feminist Economics Today*, ed. M. Ferber and J. Nelson (Chicago: University of Chicago Press, 2003), pp. 61–79; Nancy Folbre and Julie A. Nelson, “For love or money—or both?” *Journal of Economic Perspectives*, 14 (#4) (2000), 123–40; Nancy Folbre and Thomas E. Weisskopf, “Did father know best? Families, markets and the supply of caring labor.” *Economics, Values and Organization*, ed. Avner Ben-Ner and Louis Putterman (Cambridge: Cambridge University Press, 1998), pp. 171–205. Also see Clare Ungerson, “Whose empowerment and independence? A cross-national perspective on ‘cash for care’ schemes,” *Ageing and Society*, 24 (2004), 189–212.

¹⁴A number of virtue ethicists have embraced the notion of care as a virtue; see Michael Slote, *Morals from Motives* (New York: Oxford University Press, 2001). In *Dependent Rational Animals: The Virtue of Dependence and the Virtue of Acknowledging Dependence* (Berkeley: University of California Press, 1997), Alasdair MacIntyre has written eloquently and persuasively on the virtue of acknowledged dependency. Stephen L. Darwall’s *Welfare and Rational Care* (Princeton, N.J.: Princeton University Press, 2002) has utilized the concept of rational care in his welfarist ethic. While both Slote and Darwall make a substantial contribution to our understanding of the ethical dimensions of care, both employ the notion of care without stressing either the importance of the *labor* or the *relationship* of care. For MacIntyre, the labor of and relationship formed through caring are integral to his virtue of acknowledged dependency and so are especially pertinent to the concerns at hand. MacIntyre recognizes that the exercise of practical reason would be impossible without a prior attitude and labor of care. But none of these authors develops the notion of care as basis for ethics as extensively as have the collected works of feminist care ethicists. In the discussion that follows, I focus primarily on a feminist ethics of care which derives from reflections on women’s daily engagement in the labor of caring and in the emotional and relational components of a self engaged in caring.

¹⁵See, for instance, Amartya Sen, “Equality of what?” *Welfare and Measurement* (Oxford: Blackwell, 1982), pp. 353–69.

¹⁶See Martha Nussbaum, *Beyond the Social Contract: Toward Global Justice* (Cambridge, Mass.: Harvard University Press, forthcoming). For the text of a draft of the lectures delivered at the Australian National University see <http://www.philrss.anu.edu.au/tanner>.

B. ETHIC OF CARE/FEMINISM

The ethics of care emerged as a feminist alternative or supplement to theories of justice found in 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 who, traditionally, have been the primary carers) and the inevitable human dependences and interdependences too often ignored in theories that begin with adult moral agents pursuing 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 needs of another, a sense of responsibility and empathetic concern for the well-being of particular or concrete others, are at least as important as justice-based moral conceptions such as rights, impartiality, and autonomy, grounded in reason.¹⁷ Care ethics can also be especially sensitive to differences in relations of power and the inequality between caregivers and care receivers. Such awareness is needed when we evaluate longterm care policies and their impact on people differently situated with respect to ability and power. 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.¹⁸ 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.¹⁹

An ethic of care regards dependence as a central feature of human life and human relationships and interdependency rather than independence as a goal in human development. Within a care ethic acknowledging dependence is not only a foundation for subsequent ethical engagement, as it is may be when autonomy and independence are the central ethical concepts. In the last part of this chapter,

¹⁷The literature is now quite extensive. For some early, but seminal discussions see: Carol Gilligan, *In a Different Voice* (Cambridge, Mass: Harvard University Press, 1982); Nel Noddings, *Caring: A Feminine Approach to Ethics* (Berkeley: University of California, 1984); Kittay and Meyers, *Women and Moral Theory*; Annette C. Baier, "The need for more than justice" *Science, Morality and Feminist Theory*, ed. Marsha Hanen and Kai Nielsen (Calgary: University of Calgary Press, 1987), pp. 41–56; Virginia Held, *Feminist Morality* (Chicago: University of Chicago Press, 1993). For some reconsiderations and refinements see: Marilyn Friedman, "Autonomy and social relationship: rethinking the feminist critique," *Feminists Rethink the Self*, ed. Meyers, pp. 40–61; Susan J. Hekman, *Moral Voices Moral Selves: Carol Gilligan and Feminist Moral Theory* (University Park: Pennsylvania State University Press, 1995); and Robin West, *Caring for Justice* (New York: New York University Press, 1999).

¹⁸See for example Michelle Moody-Adams, "The social construction and reconstruction of care," *Sex, Preference, and Family*, ed. David Estlund and Martha Nussbaum (New York: Oxford University Press, 1997), pp. 3–17.

¹⁹For some recent work along these lines see the essays in *The Subject of Care: Feminist Perspectives on Dependency*, ed. Eva Feder Kittay and Ellen K. Feder (Totowa, N.J.: Rowman and Littlefield, 2003). This is also a point stressed in McIntyre, *Dependent Rational Animals*.

I argue that the difficulty in building alliances is in part due to the occlusion, devaluation and attempt to escape from dependence. When we view the vulnerability of dependency, rather than the interference of others into our lives as the chief moral concern, the moral discussion is reoriented to fashioning a society in which the longterm demands of care are equitably distributed and organized with attention to the relationships that give our lives meaning.

C. THE GLOBAL CONTEXT OF ETHICAL PARADIGMS

How might an ethic of care help address a global perspective on longterm care? To begin, we should see that ethical foundations that have a global reach will need to address questions of justice that pertain to:

1. the treatment of migrant care workers
2. the obligations of wealthy nations who import careworkers to poor nations who export these workers
3. the quality of care possible for those left behind when those who would otherwise be available to do carework migrate to other nations or to other parts of their own nation to take advantage of the global shifts in markets
4. the ethical issues that arise when care is considered in light of culturally different understandings of care and community.

While we need a thorough investigation of its applicability and usefulness, here I only point to plausible ways in which a care ethic is helpful. To the first concern about the treatment of careworkers, we note that a care ethics will argue for the importance of caring for the carer.²⁰ An ethic of care provides the basis and ethical motivation to attend the well-being of those who care, because care is the foundational moral relationship and activity. So the carer, (migrant or domestic) must herself be cared for, even when attending to her well-being may be relatively costly.

In addressing the ethical relations between nations involved in the exportation of care, we can utilize the insights of theorists who have argued that an ethics of care is not only appropriate to, but also uniquely poised to deal with, certain sorts of political and geopolitical issues.²¹ A language of responsibility derived from an ethics of care is well-suited to found claims of poorer nations, especially to help with the costs of care for those whom the carers leave behind.²² When

²⁰See especially Eva Kittay, *Love's Labor: Women, Dependence and Equality* (New York: Routledge, 1999).

²¹See Joan Tronto, *Moral Boundaries: A Political Argument for an Ethic of Care* (New York: Routledge, 1993). For an argument that an ethics of care is vital for international relations see Fiona Robinson, *Globalizing Care: Ethics, Feminist Theory and International Relations* (Boulder, Colo.: Westview, 1999).

²²In *Beyond the Social Contract*, Nussbaum argues that contract theories are poorly suited to provide principles to ground claims of obligation between nations that are vastly different in power and wealth. She offers a capabilities approach. While capabilities may offer a measure of what is owed, it is not clear that the capabilities approach provides a reason why more powerful nations should have any responsibilities toward the less powerful. An ethic of care offers the concept of care as a ground of responsibility.

we understand relationships of dependence and care to be central to the very notion of a moral self, we see that we that we cannot be said to care for the carer if we do not respect her relationship to her own dependents and to those with whom she has forged relationships of care. But it is not only the intimate circles of care that matter in an ethics of care. For the circles of caring relationships emanate outward and intersect with other circles of care, forming large networks of interdependencies. As a care ethic sees not isolated selves, but persons who are always in relationships, it understands the interdependence formed by even distal relationships. If we are relational selves, then as human beings our relationship to all other human beings is also constitutive of the self that we are.²³

But discussions of care ethics, as well as the other ethical paradigms that predominate in the West, have rarely come into dialogue with other cultural and ethnic traditions and belief systems. Therefore to address the fourth point above, an interchange between Western understandings of care and those of other cultural traditions must first be undertaken. If such an effort were undertaken it may be feasible to fashion the kind of discourse that will resonate in the coming years in international dialogue and debate. For a case in point consider what Dan O. C. Kaseje and Bavon Mpenda²⁴ say in speaking of long-term care in the African context. 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.”²⁵ 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.”²⁶ 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. Although the de-emphasis of the individual’s well-being may resonate with a care ethics which attempts to correct for the Western stress on independence and individualism, we need to ask if accommodating to the harsh conditions of which Kaseje and Mpenda speak should form the basis for an ethics. Should we not ask instead why such harsh conditions exist and whether they may themselves be a consequence of an injustice that needs correcting? Moving too quickly to a care ethics, which is responding to a too individualist philosophy, may cause us to bypass important injustices (both to the society as a whole and to its members *as individuals*) that may need correction.

²³One may plausibly argue that these relationships of dependency include our relationship to a nonhuman world. For an environmental ethic which adopts the importance of our dependence on the nonhuman world, see Bonnie Mann, “Dependence on place, dependence in place,” *The Subject of Care*, ed. Kittay and Feder, pp. 348–368.

²⁴Dan O. C. Kaseje and Bavon Mpenda, “The African perspective,” *Ethical Choices in Long-Term Care*, pp. 31–66.

²⁵*Ibid.*, 87.

²⁶*Ibid.*, 88.

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 the ethical resources to construct an adequate ethical response to the different situations of nations and persons. And we need to build alliances that will help redefine our values, and bring new values into our relationships and our public policy. To satisfy the need to ally ourselves with others differently situated, we need not only an ethic of care, but also a politics of difference.

IV. DEPENDENCY AS A FACTOR IN THE POLITICS OF DIFFERENCE

If we are to form alliances to address the needs of people who require longterm care and those who do the carework, the structural and social differences between people need to inform a global ethics of longterm care. The inequalities in power and wealth and the differences in the ways people live their lives across the globe give rise to differences that are not easily dealt with by presuming an equality of situation and sameness of interest that do not in fact exist.

Iris Young, who has argued for the need of a politics that does not assume an equality of starting point or of interests, that is, for a “politics of difference,”²⁷ has recently distinguished two aspects of a such a politics.²⁸ 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

²⁷Iris Young, *Justice and the Politics of Difference* (Princeton, N.J.: Princeton University Press, 1990).

²⁸Iris 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.

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. Only when granted equal standing can they have their opportunities equalized.

Dependency concerns are largely a matter of structural inequality. One should perhaps say that the inequitable distribution of the giving and receiving of dependency care is itself a prime form of structural inequality. But issues surrounding dependency play an important role in the societal cultural forms of injustice as well. A caring justice requires a 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.

Both forms of oppression, structural injustice and societal cultural injustices need to inform a global ethics of longterm care. The differences among people that make them susceptible to these injustices are all encountered in the dynamics of global and local longterm care. I briefly will look at how care and dependency needs impact upon some of the various groups for whom a politics of difference is meaningful.

A. 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 surroundings properly, and there are many more who would not be disabled were better health and environmental policies in place.

A global ethics of longterm care needs to argue for, and justify, policies that prevent the diseases and disabilities that require longterm care, but needs to do so in a manner that does not, at the same time, denigrate persons with disabilities. For example, resources to support separate and stigmatizing institutions for the blind, which often isolate them from the rest of the society, would be better spent providing the blind means to function in society such as Braille signing and other facilitations and reasonable accommodations. At the same time, when blindness results from treatable diseases, then providing

access to sanitary conditions and medical services that will prevent or cure those diseases is an unalloyed good. These preventive measures should not be conflated with prevention by means of abortion or infanticide. Treating eye disease attacks the underlying cause of blindness; abortion solely because of impairment or infanticide eliminates the individual who would have been born and so can bespeak an intolerance for human variation.²⁹

A capability approach may be helpful, insofar as this ethical paradigm argues for the greatest freedom of functioning of our basic capabilities, justifying expenditures that allow people with disabilities to have access to that which they require have the freedom to function and develop their capabilities. But a care ethics which views the welfare of an individual as that which a person who cares for that individual would desire for them is also useful. That a woman pregnant with a fetus generally wishes to have a child that will be able to exercise all its capabilities does not imply that this woman will want to abort a fetus because the child who is born lacks the capacity to exercise certain capabilities.

An ethic of care would also justify providing care where care is required, and eliminating not all dependency, but just those dependencies that undermine or interfere with the freedom to exercise whatever capacities one has or can develop. A person who cares for another with the attention required of good caring, provides care and assistance when it is needed and not when it interferes with the other's justifiable need and desire to be exercising her own agency. Both bearing the burden of unmet dependency needs, and being falsely seen to be dependent in ways that one is not, serve to 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 can and do take on these responsibilities. When, because of prejudice, ignorance or lack of social supports, people are prevented from assuming responsibilities they otherwise want to and can assume, they are shut off from a mode of flourishing, not by virtue of the inherent nature of the impairment but because of social factors. An ethic of care which sees the giving of care as a central mode of human ethical interaction, and relationships formed through care as constitutive of one's very identity justifies policies appropriate to caregiving needs and desires of people with disabilities.

Finally, assuming that achieving independence is the norm or aim of each individual is especially detrimental to those with serious mental impairments. Having a serious cognitive disability in a climate where independence is hypervalorized precludes a person's active participation in a full life more

²⁹For discussions of the difference between aborting a fetus who will be blind and preventing blindness see the essays in *Prenatal Testing and the Disability Rights Critique*, ed. Eric Parens and Adrienne Asch (Washington D.C.: Georgetown University Press, 2000).

completely than having even a very severe physical impairment. By stigmatizing dependency rather than dealing with the fact and variety of human dependency needs, we deny people with disabilities the respect and opportunity to flourish that is everyone's due.

B. RACISM

Domestically and globally, the burdens of dependency fall hardest on those who otherwise are oppressed by racism and poverty. 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. Their poor pay and the working conditions they endure enforce what Iris Young has called "the oppression of powerlessness."³⁰ 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 as a group, while called on to care for white children are often viewed as inadequate caregivers for their own.³¹ 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 article is the fact that many of the health care aides in the hallway of Partners for Care were immigrants. The importation of care workers, be they health care aides or highly trained nurses have a global impact. Rhacel Salazar Parrenas³² 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.

Care ethicists³³ have argued that a condition of justice for caregivers is that they themselves should be seen as deserving care, if not the dependency care due to a person who is inevitably dependent, care that the carer cannot provide for

³⁰In Young, *Justice and the Politics of Difference*.

³¹See Dorothy E. Roberts, "Poverty, race, and the distortion of dependency," *The Subject of Care*, ed. Kittay and Feder, pp. 277–93.

³²In Rhacel Salazar Parrenas, *Servants of Globalization: Women, Migration and Domestic Work* (Stanford, Calif.: Stanford University Press, 2001).

³³See especially Kittay, *Love's Labor*.

herself because she is attending to the needs of another. These include matters such as material resources, sometimes retraining when one's caregiving responsibilities have ended, emotional support, assistance when needed, monetary compensation, respite, etc. Elsewhere³⁴ I argue that we have an obligation to the caregiver no less than the cared for. Caring is an asymmetrical relationship in which those who are cared for are 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 carer can provide for herself as she turns her attention to the cared for. 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 much that she willingly meets its needs rather than her own, the mother herself has, in at least her earliest years, been valued by some mothering person sufficiently to survive. In recognizing the mother's own needs, especially as they arise when she defers her needs to care for those of her child, we honor the caring labor of the mothering person who nurtured her, as well as the caring labor in which she engages. 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 Hochchild's collection, *Global Women*,³⁵ of women who come to give the love they cannot give to their own children to 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 withdraw that loving care from ailing parents left behind in their native countries. Hochchild speaks of the "global heart transplant" at work in the exportation of care from poor to wealthy nations.³⁶

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 racism is not just an *additional* wrong. It is a wrong that can be discerned in the failure to recognize the universality of the caring relationship—a universality that may take different

³⁴Ibid.

³⁵Ehrenreich and Hochchild, *Global Women*.

³⁶Arlie Russell Hochchild, "Love and gold," *ibid.*, pp. 15–30.

forms but is equally powerful for all people. That wealthy and mostly white people fail to recognize (or fail to attend to) the wrong of long separations of women from their children and other dependents that enable the women to provide the care that the wealthy and racially privileged require is itself a *manifestation* of racism, and so helps to explain why a blind eye is turned to such evident wrongs.

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.³⁷ These migration patterns are part of the economics of globalization. The gap between rich and poor nations, which is largely a division along the lines of race, 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 1980.³⁸ 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 Schutte³⁹ and others have shown that 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. Facts such as these indicate the deficit of the neoliberal paradigm in dealing with matters of care. In fact this paradigm may actually contribute to the crisis in care.

C. 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

³⁷Celia W. Dugger, “An exodus of african nurses puts infants and the ill in peril,” *New York Times* (July 12, 2004), p. 1. 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 and on http://www.dfidhealthrc.org/Shared/publications/reports/int_rec/exec-sum.pdf.

³⁸*New York Times*, September 1 2001, cited in Hochschild, “Love and gold,” p. 17.

³⁹Ofelia Schutte, “Dependency work, women, and the global economy,” *The Subject of Care*, ed. Kittay and Feder, pp. 138–59.

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.⁴⁰ 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. That is why any ethical resources that are employed need a feminist cast, as a feminist ethic of care can provide. Valorizing care by sentimentalizing women's role in caregiving – neglecting to seek ways that caregiving can be de-gendered or failing that to look for ways to mitigate the negative impact that the burdens of caregiving can have on women's lives – is itself both unjust and uncaring to women.

D. 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. Some feminist care theorists have been working toward this goal.⁴¹ Such revisioning of the family, where the relationship of care is given primacy 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.

E. 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 care. They include

⁴⁰For an excellent account by feminist economists see Paula England and Nancy Folbre, "The Cost of Caring," *Annals of the American Academy of Political and Social Science*, 561 (#1) (1999), 39–51.

⁴¹See especially Martha Albertson Fineman, *The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies* (New York: Routledge, 1995).

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*⁴² documents the tragic consequences of cultural misunderstandings and arrogance in the longterm care and treatment of a Hmong child suffering from seizure disorders whose family encounters Western medicine. 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.

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 are 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 outlooks 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. This long-term care cannot be isolated from considerations of a person's family and welfare.

⁴²Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors, and the Collision of Two Cultures* (New York: Farrar Straus and Giroux, 1997).

A care ethics, with its emphasis on attention to the other and the importance of context in moral decision-making, is useful for orienting us toward cultural difference. In its emphasis on the importance of relationships, it is an ethic that may resonate well with less individualist societies than our own. But it is not sufficient. We must 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. This means that we need some ways of assessing what modes of flourishing are. A capabilities approach may be important as it is better suited to provide norms of flourishing for different cultures. Alternatively, a human rights approach may provide a floor of claims that cannot be overwritten by cultural variation.

V. BUILDING ALLIANCES TO FACE THE CRISES OF CARE

Exploring the role of care and dependency in a politics of difference 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 which requires a multifaceted approach that is international in scope suggests that there 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 caring, 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 we are 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 cannot be had at a discount. 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 personal assistants and those who are paid to assist them.

The clarion call of the disability rights movement that emerged in the early 1970's was the demand for "independence", resulting in 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 assistance and control over the aid they receive, persons with impairments can live "independent" lives.⁴³

⁴³See, for example: BCODP (British Council of Organizations of Disabled People), *Comment on the Report of the Audit Commission* (London: BCODP 1987); Mike Oliver, "Disability and dependency: a creation of industrial societies," *Disability and Dependency*, edited by L. Barton. London (New York: Falmer Press, 1989); Jenny Morris, *Independent Lives: Community Care and Disabled People* (London: Macmillan, 1993).

In cultures where independence is the indispensable ticket to full citizenship and complete 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.⁴⁴ During the interview he was getting dehydrated and very much needed a sip of water. He called for his personal assistant, who had gone outside to allow privacy for the interview. In his view, Rivas surmised, he refused the assistance she offered because accepting her help would render him a suppliant, indebted to her willingness to help. In contrast, he maintained his independence when he received water from the personal assistant—who merely served as the instrument of *his own* will.

Rivas had herself worked as a personal assistant. The daughter of a Mexican immigrant mother who had worked as a personal assistant and had to choose between taking care of her client and her own ailing mother, Rivas had chosen to help her mother by caring for the client, thereby 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, had had multiple perspectives on the subject of her research.

Of special interest to her is the significance 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 understands the import of her own invisibility to doing her job well. A good careworker, I have argued elsewhere, must make herself *transparent* to the needs of the person who depends on her.⁴⁵ 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 being a good caregiver, something realized by dint of attention and either love or sense of duty. But, Rivas maintains, the invisibility comes at a terrible cost for the careworker, for while she may take it as a labor of love, the one she cares for is more inclined to understand it as part of the job description. Becoming invisible in the way demanded of such caregiving also involves what Rivas refers to as a “transfer of authorship.” And this too comes at a great cost to the careworker. Such self-erasure, says Rivas, “is the first step toward being considered nonhuman . . . invisibility is . . . the ultimate manifestation of self-estrangement.”⁴⁶ And, though the disabled people she interviewed indicated that

⁴⁴Lynn May Rivas, “Invisible labors: caring for the independent person,” *Global Women*, ed. Ehrenreich and Hochchild, pp. 70–84.

⁴⁵*Love's Labor*, ch. 2.

⁴⁶Rivas, “Invisible labor,” p. 79.

what they sought and valued in personal assistants was their invisibility, Rivas asks with good reason, "How could something unseen be completely valued?"⁴⁷

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 having legitimate claims. Both are entitled 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 independence is valorized and dependency is stigmatized; where the caregiver is not adequately supported in her efforts to care and to be cared for.

VI. THE TRANSVALUATION OF DEPENDENCY

I propose that if we acknowledge our own dependency and vulnerability instead of demanding an illusory independence, one that can only be maintained by denying our connection to and reliance on others, then we do not need to make the caregiver invisible. We will still require the *transparency* of the caring self. Such transparency is necessary for a careworker to meet the needs of the one for whom she cares. Yet if she too is recognized as one needing and deserving care, such transparency only need mean a *deferral* of her own wishes and desires, not their obliteration. That recognition, however, is not only a matter of interpersonal relations. It requires an ethical framework by which social structures are guided.

As a vision of the independent agent has long informed theories of justice and flourishing, how can we re-imagine what it means to be dependent or to give up that independence to tend to another's dependency needs? I suggest that we want social structures predicated on a notion of justice which allows the extent and severity of our dependency needs to be rendered *indifferent* to our capacity to flourish. That is to say, whether or not we have dependency needs ought not be a critical determinant of whether or not we can lead flourishing lives. The burden of need should be neutralized by the possibility to have those needs met. Similarly the burden of meeting the dependency needs of one for whom we care ought to be neutralized by the supports offered to the caregiver.

The capabilities paradigm and the ethics of care offer the most promising resources. From the capabilities approach we may take the notion that it is capabilities that are needed for flourishing⁴⁸ and from an ethic of care we would

⁴⁷Ibid., 80.

⁴⁸Asserting this may not require a list of capabilities, but only the notion of capabilities as a way to talk about flourishing.

adopt the importance of including support for care and connection in the very structures of social organization.

But we need to do more than neutralize the burdens of dependency. We need to conceive of human dependency and the meeting of dependency needs as offering *opportunities* for flourishing. The challenge is to think of “need” in terms other than mere lack, as other than a barrier to well-being. Can we think of a need as something other than what must be overcome or satisfied prior to engaging in activities that provide real rewards?

I invite the reader to consider, by way of analogy, the need for food. Most are willing to concede that where there is enough food to feed all, the satisfaction of hunger is a requirement of justice. Furthermore, most view differences in need for food as irrelevant to the need to have hunger satisfied. A small person needing little food has no more, and no less, entitlement to have her hunger satisfied than a larger person needing more nutrition. We also view it as an injustice when farmers who grow our food are paid too little to feed themselves well. We understand the justice of underpaid hired hands who strike for better wages and better working conditions. We think it unjust for them to be asked to sacrifice the satisfaction of the very needs they work so hard for us to have fulfilled.

Similarly, I propose, that 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 may be, 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 and have care when they require it. The needs that arise from our inevitable dependency would then be seen as morally on par with those that arise from the fact that our bodies are not nutritionally self-sustaining.

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 appreciate and celebrate.

Similarly, our need for care can be, as I 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, just, and caring 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.