

Caring for Ethics and the Politics of Health Care Reform in the United States

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Abstract

It is increasingly recognized that the work of (unpaid) informal caregivers constitutes an important contribution to care delivery in the United States and in many other societies. Accounting for the range of social, economic and political circumstances in which this care is produced has become the focus of a number of academics and others theorizing the “third sector,” or the “social economy.” However, some scholars are concerned that the increasing attention paid to the role of informal economic activity will either legitimate neoliberal state withdrawal from social reproduction or facilitate continued invasive commodification of relationships that were formerly part of social life. While these are possible dangers, J.K. Gibson-Graham’s diverse economy framework and theory of community economy allow us to understand the social and economic conditions that support, rather than undermine, a caregiver’s fidelity to the process of caring. Given the size of the informal caregiving sector, it would remain an important aspect of the care economy even if the United States developed a national health care system. It is important to understand informal caregivers as economic subjects, with their desires, motivations, hopes and anxieties. What emerges from my qualitative research is an understanding of informal caregivers as ethical subjects who operate best in a network of collective recognition and support. Informal caregivers are neither self-interested economic actors nor (necessarily) victims of failed social support. Rather, they are, potentially, agents of change in a new politics of health care reform.

Keywords:

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Introduction

Informal caregiving plays a significant role in health care delivery throughout the world, especially in relation to care of the elderly and chronically ill (Wiles, 2003, p. 189). For the purposes of this article, I define informal caregivers as people who provide caring labor for others without compensation. The growing theoretical, social and political significance of informal caregivers can be placed in a larger interdisciplinary effort to understand what is variously called “the third sector,” the “social economy,” or the “informal economy” more broadly (Adaman and Madra, 2002; Biewener, 2006; Gunn, 2004). Within the discipline of geography, J.K. Gibson-Graham’s “diverse economy framework” situates formal and informal economic activity, including caregiving, within an open-ended framework of economic difference (see for example Cameron, 2000; Community Economies Collective (CEC), 2001; Gibson-Graham, 2006). The goal of these efforts has been to bring to light economic actors, processes and places that have been historically ignored in order to practice a new politics of economy and development. Through this framework, it becomes possible to imagine a politics of health care reform that starts by identifying the elements of a broader economy of care, in both formal and informal settings, in order to produce a different imagination of what is being reformed. The theory (and politics) of the community economy is the concept Gibson-Graham (2006) uses to define how the disparate elements of the diverse economy might be connected to one another.

Recently, academics and non-academics have questioned the significance and possible political pitfalls of this approach. Some caution that this “celebration” of

community aids and abets the withdrawal of state commitment to social welfare (e.g., Herbert, 2006; Joseph, 2002; Staeheli, 2005). Others fear that focusing on informal caregiving in household and community settings facilitates commodification of these previously uncommodified realms (Folbre, 2006). While the fears of abandonment or commodification are not baseless, they are articulated within a “capitalocentric logic” which imagines both of these processes being directed by an underlying structural necessity, effectively foreclosing upon the political implications of the diverse economy framework and theory of community economy for healthcare reform.¹

This article deploys the diverse economy framework and theory of community economy in the context of an action research project to generate a new politics of health care reform. A major outcome of this research project was a particular understanding of an ethics of care voiced by both professional and informal caregivers.² I argue that this common ethical commitment provides the basis for a transformative feminist politics of partial identification as well as a politics of class transformation in household and community settings (Gibson-Graham, 1996b).

Methodology

The inspiration for this article emerged from 15 semi-structured interviews I conducted with health care providers in Western Massachusetts from 2003 to 2005. The interview technique and questions were inspired by the Rethinking Economy Project (REP), a larger project directed by Julie Graham that attempted to explore the hidden, alternative and non-capitalist economic activity in the Pioneer Valley Region of Western Massachusetts (NSF BCS-9819138). Interviewees were selected using a purposive sampling technique in which paid community researchers and various community-based

organizations chose who should be interviewed. Building upon this methodological framework, I interviewed caregivers in a number of different occupational positions—physicians, nurses, health care administrators, consultants, alternative practitioners and informal caregivers. I had each interviewee identify both the social and economic forces that either constrained or enabled them to work effectively as care providers as well as the challenges and satisfactions that they associated with doing this work.

The aim of these interviews was to have informants describe their working lives as care providers. In analyzing the transcripts, two generalities emerged. First, caregivers—both professional and informal—expressed a commitment to the caregiving process that resonates with the psychoanalytic concept of the ethical act and its role in the process of subject transformation. Second, while the impetus for this ethical act is “personal” in origin, informants expressed a need to be supported in their work, to be adequately remunerated or recognized for their labor.

These thematic commonalities have implications for how we conceptualize the care economy in the U.S. and its prospects for reform. The dominant discourse regards both patients and providers as rational economic subjects consistently seeking to maximize their opportunities for consumption or income. Against this static conception of self, my research shows that informal (as well as formal caregivers) are transformed by their labor as caregivers while the nature of this transformation—whether it was life affirming or physically destructive—depended upon the social and economic circumstances that surround the caregiver. If the contemporary health care reform debate takes as its starting point an understanding of the caregiver as a fixed subject, what might

result if the caregiver were theorized as a subject constantly transformed through their labors?

How different understandings of the subjects of the care economy might lead to a different politics of health care reform is the focus of this article. The first section begins by characterizing the history of the health care reform debate in the U.S. While this debate has focused on whether care is a commodity, advocates on both sides share a common conception of patients and providers as subjects whose rational self-interest guarantees scarcity as the ontological ground of the care economy. Contemporary efforts by government administrators, private insurers, and policy experts to manage this scarcity have increasingly pushed care delivery into the household/informal economy. The second section of this article introduces recent scholarly attempts to document the size and importance of the contributions that informal caregivers—operating in household and community locations—make to elder care delivery. The theory of community economy reveals the potential for positive interaction between care’s informal and formal sectors. The third section engages with arguments that have been directed against the politics of the community economy. The principle concern is that recognizing informal caregivers either legitimates the withdrawal of state responsibility for care or leads to an increasing commodification of the life-world. In response, I argue that the persuasive power of these objections rests on a continued appeal to a capitalocentric logic—an underlying “necessity” that impels this process of state abandonment or commodification. In the final section I argue that informal caregiving labor is best described by as an ethical act. While the ethical act is the expression of individual commitment to caregiving, its successful execution depends upon enabling social and economic circumstances. Health

care reform, viewed from this perspective, revolves not around the continual quest for optimization (the miserly discourse of scarcity) but rather the creation of social conditions that allow for ethical fidelity.

The Politics of Healthcare Reform

The people of the United States have been engaged in a partisan debate over health care reform, with varying degrees of intensity, since the early 1900s (Dukakis, 2004; Engel, 2002). Déjà vu is this debate's principle characteristic, as those who advocate free market reform are repeatedly pitted against those who would prefer a government-run, "universal" alternative that would guarantee access to care as a right (Oberlander, 2003, p. 391). One could make the case that the opponents of national health insurance have won the debate. There is no right to care in the U.S., and the arguments in favor of the need for a market-based reform of health care, though vague, are consistent with an orthodoxy that regards "the market" as the solution to everything (Bourdieu, 1999). However, the mode in which health care allocation has evolved over the past 50 years complicates the picture. Sixty percent of the population secures access to care by purchasing private insurance or obtaining it through an employer as a form of compensation, though this number is expected to shrink to 50 percent within the next seven years (Ableson, 2005; Appleby, 2005; Pear, 2005). The expectation for the near future is that Medicare and Medicaid, along with other government programs, will provide access to health care for the bulk of the remaining population.³

This leaves us with something of a contradiction. While there is a partisan debate over how to reform health care, framed in relation to a looming crisis of spiraling costs, the U.S. has continued to move towards a mixed allocation system, creating a perfect

climate for each side to blame the other for the present shortcomings of the system. I would argue, however, that what keeps this debate in a state of impasse is a shared conceptualization of the principal subjects of care—patients and providers.

The problem of rising healthcare costs is seen as a function of patients' and providers' rational self-interest. The concept of *moral hazard* asserts that patients, when they are not financially responsible for care costs, consume as much care as possible. The response to moral hazard is the imposition of co-payments to constrain patient demand without (hopefully) adversely affecting patient health. The imposition of co-payments has been universally adopted by private insurers and governmentally based care allocation programs. The concept of *demand inducement*, on the other hand, describes how providers' self-interest directs the diagnosis and treatment of illness to maximize income. Again, in response, both government administrators and private insurers have, since the 1970s, adopted a system of capitated payments that sets limits on how much hospitals and physicians will receive for particular treatments (Dranove, 2000, 2003).

On both sides of the debate, for Medicare administrators and executives at the HMO Humana, the fundamental problem will always be one of constraining patient demand and controlling costs. The true efficacy of moral hazard and demand inducement lies in their ability to function as the effective limit of the health care reform debate. If constraining demand and controlling costs are the only logical responses to the excessive demand of patients and providers, the choice between conceptualizing health care as right or a commodity is effectively reduced to whether one prefers explicit rationing by the state or the implicit rationing of the market. The problem here is that co-payments and capitation along with productivity audits and the limitation of patient provider choice—

the principal cost control measures of Health Maintenance Organizations (HMOs)—may work to constrain and contain, but they also re-enforce the idea that there is not enough care to go around. In other words, the shared essentialist assumptions about patients—with an endless desire for care—and providers—directing care to always maximize income—install *scarcity* as a dominant condition. The ontological status of patients and providers as rational utility maximizers ensures a circularity to the reform process because their demands will always need to be constrained and controlled. To paraphrase Uwe Reinhardt’s (2000, p. 161) observation, “there will always be health care reform...and it will always fail.”

This self-imposed austerity has other effects as well. Dranove points out that much of the cost savings achieved by HMOs in the 1990s were related to reducing the length of hospital stays, which was partially an effect of technological innovation, such as the development of less-invasive procedures and refinements in the administration of anesthesia. These innovations have allowed HMOs to favor outpatient treatment (Dranove, 2000, p. 43), which leads Anders (1996) to suggest that the cost savings associated with managed care had as much to do with redistributing the labor of care as with changing technology. Outpatient care frequently shifts the burden of post-surgery recovery from the hospital to the household, from paid to informal caregivers in the home. One could see this practice, of “quicker and sicker” discharge, as a particularly pernicious form of privatization. This move to the third sector, the household and community, is a symptom of how we conceive of the care economy.

What should not be missed, however, is that informal caregiving—taking place in homes and other non-commercial settings, involving non-professionals who provide care

on a voluntary basis—are currently external to the spaces and actors that concern the health care reform debate.⁴ Both sides of the health care reform debate are focused almost exclusively on a miserly consideration of how to best economize on formal sector care costs. For our purposes, if the health care reform debate is at an impasse, perhaps an exploration of the informal sector might allow for a different approach to health care reform. Informal caregivers are, after all, not financially compensated for their efforts and therefore cannot be understood through the lens of demand inducement.⁵ Assessing the size and importance of the informal caregiving sector might, at a minimum, allow us to see previously unrecognized resources. A more ambitious proposition is that informal caregivers might supply us with an alternative conceptualization of caregiving subjects.

Assessing the Size and Situating the Informal Caregiving Sector

In a groundbreaking study, Arno *et al.* (1999) set out to quantify the amount and value of informal elder care produced in the U.S. They analyzed primary data from the Survey on Income and Program Participation (SIPP), the National Survey of Families and Households (NSFH), and the National Long-Term Care Survey (NLTC). On the basis of these surveys, they estimated the number of informal care providers and the hours they spent producing care for the elderly population (Arno *et al.*, 1999, p. 183). Following Luxton (1997), they assigned different hourly wage values to informal caregiving, from \$5.15 an hour to \$11.20 an hour, they estimated that informal caregiving might be valued between \$115 billion and \$288 billion per year. In dollar terms the middle estimate (\$196 billion at \$8.18/hr) exceeds the value of nursing home and (paid) home health combined (\$105 billion) (185).

The Area Agencies on Aging, established in 1973 as an outgrowth of the original Older Americans Act of 1965, have been given the responsibility of educating the population about care resources for older Americans. In a recent policy brief, the National Association of Area Agencies on Aging (N4A) restated the magnitude and importance of informal caregiving. Given the extent of informal care and its social costs, it is surprising that the N4A concludes that:

Despite vast research on family caregivers, widespread awareness of the volume of family care, and general agreement that family care is necessary to balance the costs of long-term care, a comprehensive policy on family care of frail older adults has not emerged. A patchwork of family support programs of various kinds does, however, exist. (N4A, 2004)

In light of Arno's statement that the formal/market elder care sector is a supplement to the much larger informal sector, one is tempted to see in this policy statement a call for a new type of thinking rather than increased levels of financial support. Given the sheer size of informal caregiving one is left to wonder if what is required is a more fundamental rethinking of the economy of care itself.

Donelan *et al.* (2002) took a different tack in relation to this issue, surveying actual informal care providers. She and her fellow researchers found that informal caregivers feel generally ambivalent about their experiences as caregivers. On the one hand, they recognized foregone income and career opportunities as a result of providing care. Informal caregivers readily spoke of the physical and emotional consequences of caregiving as well. On the other hand, for most caregivers, caregiving was also profoundly meaningful and satisfying. Donelan's study concludes with policy recommendations that would assist caregivers in their efforts. Some of these policy recommendations are unsurprising in light of the financial and technical difficulties associated with informal caregiving. These include more formal training for caregivers,

better access to paid assistance, better information and more “public awareness of the value of caregiving.”

Donelan *et al.* pursues this last point a bit further in their conclusion—speaking of a need for a public to understand not only the challenges but also the rewards of informal caregiving.

For years we have conceptualized the caregiving experience as something stressful. While it is clear that this is true, it is also true that caregivers see many positive benefits, including even expressions beyond “duty” and “privilege.” In an aging population, more and more Americans will assume the role of caregiver. We need to build public awareness of the societal and personal value of rendering these services. (Donelan *et al.*, 2002, p. 231)

Informal caregivers are here described as uniquely motivated subjects—“beyond duty and privilege.” While we will return to the question of what motivates the subject of caregiving, and what is beyond duty and privilege—it is worth considering the split nature of the caregiving experience. Informal caregivers can experience their labor as either onerous and damaging or as meaningful and fulfilling. How might we account for this difference?

The Community Economy of Care

For several years as a member of the Community Economies Collective (CEC) I was involved in a qualitative research project entitled the Rethinking Economy Project (REP), directed by Julie Graham (NSF). The goal of this collaborative research effort was to document the significance of the formal, hidden and alternative economies of the Pioneer Valley in western Massachusetts in order to enliven an alternative approach to economic development (Graham, Healy and Byrne, 2002). The principle inspiration for this project was J.K. Gibson-Graham’s (1996a) *End of Capitalism*, in which they point

out that while other aspects of society and culture, especially identity—race, sexuality, gender—have increasingly been understood as both discursively constructed and iteratively differentiated, the economy remains an undifferentiated monolith, functioning as a limit to the possible meanings of difference in social identity. To counteract this, the CEC’s qualitative research effort explored the full range of economic activity. What emerged from this exploration was a simple open ended representation of economic space (see figure 1).

<INSERT FIGURE 1 HERE THE DEF?>

The diverse economy diagram describes different organizational forms, drawing on a particular reading of Marx’s class categories to recognize that firms, households and community sites can be organized in any productive social relation—from cooperatives to contemporary instances of slavery.⁶ Given this range of organizational forms it is also possible to conceive of a range of remuneration practices—from conventional wages, to cooperatively determined compensation, to the “mental wages” of a volunteer. This heterogeneity appears in a space of exchange as well. The contemporary economic landscape has many instances of non-market exchange as well as formal and informal barter networks. One should take note also that the state can be theorized as an economic actor within the diverse economy framework—engaged in non-market transfer payments and alternative capitalist enterprises, for example. In this differentiated landscape, capitalist economic activity (or the state, for that matter) is simply one process among many.

While the diverse economy framework attempts to describe and empirically verify a heterogeneity of organizations, exchange processes and compensations, the theory of community economy attempts to imagine a process of social transformation or development that involves the formation of experimental linkages within this heterogeneity. One organization that I encountered in the course of my research was Holyoke Health Center (HHC). HHC is a community health center founded in 1972 to serve the needs of the poor, largely Puerto Rican population of Holyoke, Massachusetts. In the diverse economy framework it would be considered an alternative state capitalist enterprise that employs a salaried physician and support staff to produce health services for insured and uninsured patients. However, as interviews with executive director Jay Breines revealed, it was an organization that functioned in collaboration with the broader community. Through the diverse economy framework we can see HHC as a nodal point that operates by connecting with paid and unpaid economic actors, market and non-market activities, and capitalist and non-capitalist spaces. For instance, HHC collaborated with volunteer-based community organizations to produce a map of point-source pollutants that exacerbated the asthma epidemic in their community. More ambitiously, Breines began in 2002 to negotiate with both Dell and the city to provide computers and internet access free or at low cost so that expectant mothers who made use of HHC services could form a peer support network.⁷ Breines saw in these collaborative efforts a way of not only improving public health but also *developing* a different kind of community wellbeing, one that revolves around linking the health center to non-market social locations, forming a community economy of care.⁸

The diverse and community economy concepts allow us to recognize the contributions of informal caregivers and to reframe the health care reform debate from the perspective of a post-capitalist politics. However, it must be recognized that there is a dispute within feminist geography, and feminist theory as a whole, as to the meanings of care and community, and the political implications of recognizing the feminine economic sphere. Indeed, some regard this recognition of the diverse and community economy as having inherent dangers.

Resistances and Objections to the Politics of Recognition

When members of the CEC have presented the diverse and community economy concepts to a popular or academic audience, one typical response is skepticism about the importance of economic difference. The most commonly voiced objection is that while it is important to recognize the informal economy or informal caregivers, there is a cost associated with this “celebration” (Gibson-Graham, 2006). The fear is that increasing the visibility of care in the community economy will either serve to legitimate the social policies of neoliberal rollback or aid in the further commodification of care.⁹ These cautionary injunctions preempt the alterity of informal caregivers as subjects, positing them as subordinate to or reinforcing the predominance of capitalist economic space while misreading the theoretical motivations behind the diverse economy framework and the theory of community economy.

1. Community Economy as an Apology for Neoliberalism

Lynn Staeheli (2005) notes the proliferation of the terms “care” and “community” in a variety of academic and non-academic contexts. Indeed, she argues that it is difficult

to escape from the notion of careful market(ing) and compassionate conservatism. In her view, there is something unsettling, perhaps even dangerous, about the readiness with which we embrace notions of care and spatialize it in relation to an equally nebulous concept of community. Care and community are difficult to object to and, for precisely this reason, serve to mute antagonisms in the workplace and in relation to governance. Staeheli has voiced concerns repeated elsewhere (e.g. Herbert, 2006) that community-based notions of care serve as an ideological cover for the state to withdraw from the provisioning of social welfare. Community, in this way, becomes the repository of all forms of care that the state abandons, regardless of whether or not the (usually local) community has adequate resources to address particular problems.

Staeheli's position seems consonant with Joseph's (2002) argument that community serves as a necessary supplement to capitalism. For Joseph, melancholic attachment to the lost community legitimates the existing putatively "capitalist" social order. Community becomes a mythical epoch prior to capitalism rather than a set of social relations that continue to make capitalism and its contradictions possible. As the state is brought more thoroughly into alignment with the agenda of the capitalist class (in the guise of neoliberalism or the austerity measures of the International Monetary Fund) there appears to be an even greater need to evoke a community that is lost (Joseph, 2002, p. 12).

Staeheli and Joseph's theories appear to quell any hope we might place in the diverse and community economy concepts. Notions of care and community are discursively constituted in a way that aligns them with the politics of apology or

nostalgia. Community becomes the space saddled with the contradictions of capitalism and the obligations refused by the contemporary state.

2. *Community Economy and Commodification*

While Staeheli and Joseph are concerned with state abandonment, Folbre (2001) is concerned with an entirely different dynamic—the gradual commodification of caring labor. Concepts of care and community are here not (only) threatened with state abandonment but instead with invasion by the market. Folbre is committed to a project of accounting for the feminine sphere as exemplified by her proposal to have a Dolly Jones Index (DJI) (Cameron and Gibson-Graham, 2003, p. 149; Folbre, 2001, p. 66).¹⁰ This project, however, is tempered by her repeatedly voiced concern that caring labor, in all its forms, has become increasingly commodified. In her view, women's entrance into the wage economy since the 1970s has been complemented by a gradual substitution of the market sector for the household (Folbre 2006). Efforts like Arno *et al* seek to increase the visibility of informal caregiver contributions by quantifying their value in market terms are worrisome because they unwittingly serve to legitimate the transfer of household goods and service production into the market sector. Rather than an absent state, the threat is configured as an overbearing market that threatens the life world with an ironic commodification, as households and communities pay for services that they once produced for themselves.¹¹

Complementing this process of commodification, Pavlovskaya (2006) argues that the language of “flexibility” that swept through the business culture in the 1990s has made its way into the household by way of a popular literature that links self-improvement, child development, and time management. While well-to-do households

struggle with management, economically marginal households are left to manage home life responsibilities; one or more jobs in the formal sector, as well as coordinating other streams of income (see also Fraad, Resnick and Wolff, p. 1994). Pavolovskaya argues that if a new obligation like caring for an older parent emerges in such a household, the rate of exploitation of persons charged with this labor, frequently women, is likely to increase.¹²

Care in the Community Economy: From Visibility to a Politics of Community

Economy

I am tempted to agree with Staeheli, Joseph and Folbre in arguing that neoliberalism and shifts in the relation between the household and formal economy could have adverse impacts on informal caregivers. The argument I wish to make in this section is not predicated on refuting the threats that each describes. Rather, the space for the alternative approach to health care reform must hinge upon questioning the totalizing logic instantiated in these arguments. Without this integrative moment we are left with a vision of the care economy that is inexorably directed by “capitalist” imperatives.

Parallel to these capitalocentric visions of abandonment and invasive commodification is the logic that informs moral hazard and demand inducement. Recall that the individual essentialist depiction of patients and providers as rational utility maximizing individuals is what makes scarcity a central concept for both sides of the health care reform debate, and that this notion of a general social condition of scarcity is derived from the essential character of individuals. Staeheli, Joseph and Folbre appear to articulate a complementary capitalocentric logic which operates on a structural level in which the necessity of continued capital accumulation compels the neoliberal state to

withdraw social reproduction in order to minimize its demand for capital. Likewise, it is the need for economic growth that compels the progressive commodification of affective labor. In this vision it is capital that is a scarce resource that must be conserved for the sake of “productive” economic activity. As long as one operates from within the perspective of this logic it is difficult to conceptualize informal caregiving, the “third sphere,” or the community economy as anything other than the victim of capitalocentric logic as it plays itself out.

To return to a critical point raised by Pavlovskaya, the withdrawal of state support and/or increased participation in the market (wage) economy *could* result in intensifying exploitation of informal caregivers at home. She, like Fraad Resnick and Wolff (1994) and Gibson-Graham (1996a), represents this as a contingent possibility, not an inevitability. It is equally possible to imagine that the additional challenges placed upon informal caregivers might provide the impetus for transformation within the household economy in a way that enables, rather than threatens, the capacity of informal caregivers. In the concluding section I argue that such a process is best understood as the relationship between “class transformation” and the way caregiving, as an ethical act, reconfigures the subject.

Caregiving Stories: Emerging Communalities, Ethical Fidelity

Ashley at the time of her interview was a 23-year-old who had been involved in informal and formal elder care provisioning for six years. Because her thoughts on caregiving were so clearly articulated and resonated with other care providers I interviewed, they proved to be instrumental in crystallizing my thinking about the relationship between informal caregiving, ethics and the politics of class transformation.

Ashley became involved in informal caregiving after her grandmother's fall and hip fracture resulted in a series of progressive complications—immobility, infection and colitis. Ashley, along with her mother and stepfather, began to care for her grandmother, helping her with everything from basic functioning to administering medicines over the protests of a patient who insisted that she was still capable of caring for herself. I asked if she felt pressured to perform this labor.

Q: Did you feel, I mean forgive me for pressing this, but did you feel coerced into that?

Ashley: No, not at all.

Q: That's something you wanted to do.

Ashley: And I'll tell you she wasn't a very nice woman her whole entire life.

Ashley felt that her grandmother's mean spiritedness was a function of her traditional beliefs about gender. Her beliefs were evident in the different way that she treated her son and her daughter, Ashley's mother. To her son, to whom she had given everything including money for a college education, she expected nothing and he was not involved in providing care. From her daughter, to whom she had given nothing, she expected everything as a matter of course. When her grandmother said "I don't need help and I am just fine," Ashley explained that her real meaning was also "and even if I did need help, I shouldn't have to ask for it."

Following Fraad, Resnick and Wolff (1994) one can readily identify Ashley's household as an instance of a feudal class process. For Marx, feudalism, like capitalism and slavery, is an exploitative class processes. Exploitation, rather than denoting particularly demeaning or hurtful forms of labor, simply refers to the formal condition in which those who produce surplus are not the first receivers of the wealth. In traditional

feudalism this exploitative relationship is cemented through the reciprocity of the lord and through normative values that insist on a natural order in the economy of the household. One might read in Ashley's grandmother's attitude towards care an instance of "disavowal"—an acknowledgement of the feudal relation and a simultaneous "acting as if" there is no (exploitative) class relation.¹³

Ashley's story appears to confirm many of Staeheli and Joseph's concerns. Since care is not conceived as a social problem it falls upon the shoulders of individuals in the family in a way that reinforces a feudal class structure. From this perspective, Ashley's experience is only one of victimization. While such an assessment may in fact be true, imagining it as a fixed and inevitable condition prevents us from perceiving changes in the nature of the caregiving process. At one point in our interview she began to describe a subtle shift in the attitude of her grandmother.

Ashley: Well, for my grandmother, she was the old Polish lady that didn't want anybody helping her doing anything. I mean, she would say, "Oh no no, hon, I'll clean it up," but she obviously couldn't, because she couldn't walk. And she never had enough...I don't think she ever had enough time to get over that.

Q: She might have if she had lived longer.

Ashley: Every time something happened, we would say, "No, no, no don't worry about it," deal with cleaning her up first, clean up the mess, and we would just keep telling her, "No, it's fine. And we love you and that's why we're here, and that's...you know we're going to help you in whatever way we can." And actually, towards the end she did start letting us help, because she knew that she couldn't do much for herself.

This shift in attitude accompanied an increasing degree of cooperation between Ashley, her mother and stepfather. While the caregiving burden remained, their cooperative response eased the physical and emotional dimensions of the labor. In class terms this suggests a shift from a feudal to a communal household class process. In a communal

household class process, goods and services are collectively produced and appropriated. In this light, the care collectively produced by Ashley, her mother and stepfather becomes a surplus that is donated as a gift to the grandmother. The status of the labor as a gift does not mean, however, that Ashley and her parents felt that their labor was purely voluntary, or that there was no sense of obligation that attended their labor. Echoing the sentiments of other informal caregivers, Ashley saw her caring labor as something she both needed to do *and* something she wanted to do. How is it possible to experience freedom and obligation simultaneously? How can Ashley feel free to do what is also necessary?

Ashley supplied a partial answer to this question when she described her involvement with a community-based adult day care center located in Greenfield, Massachusetts. The purpose of the adult day care center was to provide temporary respite for informal caregivers. Elders suffering from Alzheimer's disease could be dropped off at the center so that informal caregivers could rest or attend to other obligations. Caregivers can visit the facility to learn how to be more effective and less stressed by their experience.¹⁴ As Ashley became involved in the center she developed and ran a series of seminars that dealt with a variety of topics from basic care issues to how to deal with and overcome the sense of shame that comes with the loss of integral capacities, such as feeding and toileting oneself. She very much saw the center as a community-based space whose function was to support and augment the efforts of the primary informal caregivers. One could read this through the diverse and community economy concept as an interaction between the volunteer and household economy. Viewed from this perspective, we can see the workers in the community center as engaged in a gifting of their time and labor to community members. An alternative proposition would be to

see this as an extension of a communal household class process into the community. Ashley's involvement in the informal caregiving is represented diagrammatically in figure 2.

<INSERT FIGURE 2 HERE>

It is only by situating Ashley's labor in the context of her familial and community support structure that we see her as something other than an abject subject. I do not mean to suggest that Ashley, as a communal subject who makes a gift of care, experiences only fulfillment in relation to the process. She clearly described the work as physically exhausting and typically thankless, but its communality allowed her to negotiate the experience without being destroyed by it. In the same way that the Holyoke Health Center became more effective by insinuating itself into the community economy, Ashley's experience as an informal caregiver became more bearable as a result of the support network she created. Finally, it was also clear that Ashley, in committing herself to this work, was transformed by caregiving.

Ethically Based Health Care Reform and Community Economy

As I listened to Ashley's story, along with those of other caregivers that I interviewed, I became increasingly convinced that informal caregiving bears a resemblance to the ethical act as it has been described by contemporary social theorists, especially those who have returned to Lacan's appropriation of Kant (e.g. Copjec, 1995, 2000; Zupancic, 2000; Žižek, 1994—henceforth new Lacanians). For new Lacanian theorists, ethics are distinct from morality/normative values because they involve an act.

The act differs from the [ordinary/pathological] "action" in that it radically transforms the bearer (agent). After an act, I am "not the same as before." In the act, the subject is annihilated and subsequently reborn (or not): the

act involves a kind of temporal eclipse of the subject. (Zupančič, 2000, p. 83)

One implication of this definition is that an ethical act cannot be understood as self-interested, insofar as the subject who faithfully fulfills the act is no longer the same person who undertook it. New Lacanian theorists typically use extreme acts performed by historic figures to define the ethical subject. Copjec (1995) uses Antigone as an example of an ethical actor. She defied the law to bury her brother at the cost of her life. For Žižek (2000) the ethical act is transformative because of its transgressive law-defying quality.¹⁵ It is precisely this transformative/transgressive quality of the ethical act that leads Kant to designate it as a free rather than pathological, act. The ethical act is radically different from ordinary self-interest but it is also defined by the subject's departure from the normative order. I would assert that informal caregivers appear to describe the caregiving process as an ethical act.

Given the dramatic figure of Antigone, one is initially hard-pressed to imagine how the ethical relates to the everyday actions of informal caregivers. Nevertheless my interview with Ashley, and with other informal caregivers, seemed to resonate with this ethical self-understanding. Ashley saw her caregiving as deeply meaningful and profoundly transformative, something that was repeated in my interviews with other caregivers. She clearly would not be the same person without those experiences. What really convinced me of the "ethical" nature of caregiving, however, was the way in which it involved transgression. A turning point in the interview came when Ashley began to describe how she and her grandmother accommodated themselves to her reduced basic functioning. Ashley's voice, which had an air of professional reserve throughout the interview, momentarily gave way to a deeply affected tone when she spoke of the process

of needing to continually re-enforce the idea that to receive help with toileting or feeding oneself is not to become suddenly abject. At the same time, Ashley was clear that it was also a process for her to become comfortable helping her grandmother, and then others, with these basic bodily functions as well. Do we not have, in this instance, an act (or series of acts) that transgresses a fundamental barrier between self and other that, in the end, remakes the subject?¹⁶

The caregiver as an ethical subject is distinct from the subject as she is imagined in the theory of demand inducement. Ashley is not caring out of self-interest nor does she imagine herself as a subject with a consistent experience—caring giving is satisfying and onerous, fulfilling and difficult. In place of an immutably self-interested subject conspiring to maximize their enjoyment, we have a subject that is changed through the labor of care. Likewise, Ashley as a caregiver is not an agent-less victim of a neoliberal state that has withdrawn from its social reproductive obligations. She, and the rest of her family, was resourceful in caring for their grandmother, orchestrating a cooperative response and drawing upon creative resources while engaging in caregiving—an activity that Ashley says she feels she must do while also being something that she wants to do. Ashley is neither a self-interested actor nor a victim of a failed/absent social response to caregiving. She is, rather, a subject who is able to experience the necessity of caring as aligned with her desires. It is her receptiveness to being transformed by this labor that makes her ethical while it is the support from the broader community that sustains her.

Other countries that guarantee health care as a right still have a large informal care giver sector. Even if the U.S. were to develop a large, well-funded public sector, informal care would remain necessary. Likewise, this would still be true even if we

developed a perfect care market. Because the informal care sector will remain necessary, freedom is predicated upon developing a way of caring that does not alienate the caregiver from necessity. If the mainstream approach to health care reform revolves around constraining self-interested care providers, a new approach would focus on creating social conditions that *enable* caregivers to perform their labors in fidelity with their ethical commitments. This process would work in one way at the level of individuals like Ashley and another at an institutional level like HHC. Thanks to the diverse economy framework and theory of community economy, however, we can see in both instances how reform would revolve around increasing the capacity of individuals and institutions to freely and faithfully respond to the need for necessary care. The economy of care then becomes one that is predicated on the creation of network generosity and associative exchange rather than merely revolving around conservation of effort in an economy of scarcity.

The diverse economy framework and theory of community economy recast the politics and process of health care reform as a marshalling of resources in order to generate a sufficient response to care needs in specific instances and locations. In contrast to the bureaucratic procedure with its application of various proscriptions that are imagined to fix the health care problem (that will work regardless of circumstances), in the new approach to health care reform both the definite need and the available set of solutions are understood as inherently variable and, therefore, open to a deliberative ethical response (Gibson-Graham, 2003a; 2003b). It is entirely possible that a family, community or even a national community may still fail to meet all needs but this failure is experienced in a radically different way—rather than a failure to embody the singular

solution to the problem of health care allocation, the process of articulation fails or succeeds in relation to particular circumstances whose nature is indeterminate.¹⁷

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Figure 1 (Gibson-Graham 2006, 71).

<i>Transactions</i>	<i>Labor</i>	<i>Enterprise</i>
MARKET	WAGE	CAPITALIST
<p><i>ALTERNATIVE MARKET</i></p> <p><i>Sale of public goods</i> <i>Ethical 'fair-trade' markets</i> <i>Local trading systems</i> <i>Alternative currencies</i> <i>Underground market</i> <i>Co-op exchange</i> <i>Barter</i> <i>Informal market</i></p>	<p><i>ALTERNATIVE PAID</i></p> <p><i>Self-employed</i> <i>Cooperative</i> <i>Indentured</i> <i>Reciprocal labor</i> <i>In kind</i> <i>Work for welfare</i></p>	<p><i>ALTERNATIVE CAPITALIST</i></p> <p><i>State enterprise</i> <i>Green capitalist</i> <i>Socially responsible firm</i> <i>Non-profit</i></p>
<p><i>NON-MARKET</i></p> <p><i>Household flows</i> <i>Gift giving</i> <i>Indigenous exchange</i> <i>State allocations</i> <i>State appropriations</i> <i>Gleaning</i> <i>Hunting, fishing, gathering</i> <i>Theft, poaching</i></p>	<p><i>UNPAID</i></p> <p><i>Housework</i> <i>Family care</i> <i>Neighborhood work</i> <i>Volunteer</i> <i>Self-provisioning labor</i> <i>Slave labor</i></p>	<p><i>NON-CAPITALIST</i></p> <p><i>Communal</i> <i>Independent</i> <i>Feudal</i> <i>Slave</i></p>

Figure 2

<i>Transactions</i>	<i>Labor</i>	<i>Enterprise</i>
MARKET	WAGE	CAPITALIST
<i>ALTERNATIVE MARKET</i> <i>Sale of public goods</i> <i>Ethical 'fair-trade' markets</i> <i>Local trading systems</i> <i>Alternative currencies</i> <i>Underground market</i> <i>Co-op exchange</i> <i>Barter</i> <i>Informal market</i>	<i>ALTERNATIVE PAID</i> <i>Self-employed</i> <i>Cooperative</i> <i>Indentured</i> <i>Reciprocal labor</i> <i>In kind</i> <i>Work for welfare</i>	<i>ALTERNATIVE CAPITALIST</i> <i>Non-profit</i> <i>(Adult day care center)</i>
<i>NON-MARKET</i> <i>Household flows</i> <i>Gift giving</i>	<i>UNPAID</i> <i>Family care</i>	<i>NON-CAPITALIST</i> <i>Communal</i> <i>(Ashley's household)</i>

¹ Gibson-Graham (1996a, 6) argue that the subordination of the household economy in economic theory is an instance of capitalocentric thought. In their view, conventional economic and development discourse and the anti-capitalist left are fixated on capitalism:

When we say that most economic discourse is “capitalocentric,” we mean that other forms of economy (not to mention noneconomic aspects of social life) are often understood primarily with reference to capitalism; as being fundamentally the same as (or modeled upon) capitalism, as being deficient or substandard imitations; as being opposite to capitalism; as being the complement of capitalism; as existing in capitalism’s space or orbit.

Gibson-Graham argue that the academic and popular left cripples itself by envisioning capitalism as an omnipresent system and that other spaces, practices, beliefs and political convictions wittingly or unwittingly reproduce this system. Capitalocentrism places capitalism in the position of the “master signifier,” where it becomes synonymous with the economy as such.

² The argument I make in favor of an ethically directed approach to health care reform applies to professional caregivers with equal facility. I choose to focus on informal caregivers here because their labor can more easily be recognized as labor performed for reasons other than self-interest.

³ Both Medicare and Medicaid were created in 1965 with the passage of the Older Americans Act (OAA). The initial expectation was that these programs would be superceded by a national health insurance program (Gottschalk, 2000). Medicaid and Medicare target two different populations. Medicaid is a program designed to give the permanently disabled and indigent access to medical care. It is governed on the basis of means testing and while the funding for Medicaid comes from the U.S. federal government, the dispersal of this care-money is directed by individual states. Medicare, in contrast, is a universal entitlement directed at the retired population over age 65. Medicare provides access to care for older Americans regardless of income levels. The “Older Americans Act Amendment,” passed in 2003, expanded the Medicare system by creating a system to help seniors pay for pharmaceuticals.

⁴ Donelan *et al.* (2002) describe the range of tasks performed by caregivers operating in a household setting—from the changing of bandages to the administration of complex drug or physical therapy regimens. Several of my formal and informal sector informants also pointed out that informal caregivers frequently “manage” the care service for elderly or chronically ill patients—minding and attending appointments, acting as liaison and chauffeur. While some of these tasks may seem relatively simple, it is frequently balancing a caregiving commitment in its entirety, along with the rest of their working lives, that becomes truly challenging.

⁵ The point here is not to argue against the idea that some caregivers are motivated by economic self-interest. Rather, my argument here is that bureaucratic management of demand inducement *presumes* its universality. Economic self-interest appears here as an objective fact about human subjects while fidelity to ethical principle is regarded as an unsubstantiated and suspect human motivation. From my perspective, there is no greater proof of the hold that economic conceptions of human nature have on the discourse of health care reform than the difference in the apparently factuality of “self-interest” and “ethical commitment.” It is precisely for this reason that the motivations of informal caregivers becomes of critical importance. It is difficult to see their actions falling under the sign of rational self-interest.

⁶ One only need think of forced labor without freedom of contract in prisons to recognize the prevalence of slavery in the U.S. though this is not the only space where it occurs.

⁷ To date, this effort has not come to fruition. The idea, however, was that computers/internet access might become useful in these households in other ways.

⁸ When HHC won a grant to build a new 15 million dollar facility, the board chose to locate the new facility in downtown Holyoke. The completed facility, La plaza de salud, not only housed their clinic but attracted the first pharmacy in a number of years to locate in downtown Holyoke, as well as making space available for the first dental clinic to be located in Holyoke in many years. In time, La plaza de salud also attracted other businesses to empty buildings in the vicinity. As Savage (2004) points out, health care is a major employer in many cities. While health care is typically regarded as a “social reproductive expense” it is equally possible to see the health care sector as a major employer with its own multiplier effect, creating demand for other services. While Savage (2004) alerts us to the possibility that we could conceive of health care as a major employer, the diverse and community economy concept allows us to enlarge our vision of what that economy is and where it takes place. While health care is a major employer, the type of connections that local care institutions like HHC could potentially produce with individual informal caregivers and community organizations alerts us to the prospects for health care reform at the local scale. This alternative imaginary of health care reform (as development) has definite implications for the informal caregiving economy. It provides us with a different stance from which to approach the problem while not prescribing any fixed or definite course of action since the resources that might be brought to bear in the development of a community economy of care are going to vary by location. The formal, diagrammatic representation of the diverse economy becomes Thrift’s (2004) “question generator,” not a prescription but a way of thinking.

⁹ See Peck (2002) for a description of neoliberal “rollback” of state welfare provisioning and its relation to continued capital accumulation.

¹⁰ The purpose of the DJI, like its counterpart in the market sector the Dow Jones Index, would be to give one a sense of the state of the household and communities. The Genuine Progress Indicator (GPI) is a similar idea that tries to get at the state of the entire economy by quantifying the health of the non-market sector as well as adding a debit to national accounts for spending on crime, crime prevention and environmental remediation (see <http://www.rprogress.org/projects/gpi/>).

¹¹ Hochschild (1997) sees an irony in this process as it accelerates. As “feminine labor” enters the sphere of the market, work-life comes to take on the qualities of home. The workplace, in her view, demonstrates and performs care and concern for clients and workers (in order to ensure productivity). Simultaneously, the necessity of the two-income household and the increase in hours worked create pressure for time spent in household labor to be increasingly regimented and industrial in character as the time available for this labor becomes scarce. Under such conditions it is entirely possible to conclude, as Hochschild does, that the long hours at work are a refuge from increasingly dysfunctional home life.

¹² The rate of exploitation in a capitalist enterprise is an expression of the difference between the necessary labor performed by a worker (the value of their wage) and the surplus to be actualized in exchange. The rate of exploitation is easy to calculate in such a context since it can be deduced numerically (the difference between wages and the value of the total product produced for exchange expressed as a ratio). Nevertheless it is possible to speak of a rate of exploitation in class processes that are not involved in production for exchange. Here the rate of exploitation would be the difference between what amount of labor power would reproduce the individual performing the labor and the extra value that is subject to appropriation (e.g. Gibson-Graham, Resnick and Wolff, 2001).

¹³ My interview with Ashley provided insufficient information to really determine who occupied the position of feudal appropriator. It would be possible to identify the grandmother as the matriarch of the family who “demanded” this sort of caring labor from her younger female relations. Another theoretical possibility is to think of Ashley’s parents occupying to position of feudal appropriator who then direct that a certain portion of household labor be performed in the service of Ashley’s grandmother.

¹⁴ As Patch Adams (1998) observes, it is precisely the feeling of being “indispensable” to another person that causes caregiver burnout. Informal caregivers who are sole providers for patients can hardly avoid the feeling of being indispensable. Ashley pointed out that this increases the chances that a caregiver may become emotionally or physically abusive toward their charges.

¹⁵ The law can be understood here both as a social institution that governs and regulates behavior and, from the perspective of new Lacanian theory, as something that exists in the socio-symbolic order. Speaking beings are subject to the laws of language that define them as subjects.

¹⁶ I am also left wondering if this is in keeping with Callard’s (2003) and Kingsbury’s (forthcoming) injunction to not domesticate the insights of psychoanalytic theory. Her intention was to suggest that psychoanalytic theory is not simply another way of describing the subject as socially constructed, contingent and therefore pliable or receptive to radicalization. As she rightly insists, psychoanalytic theory is as much about the “stuckness” of the subject: repetition, neurotic malady, feelings of shame and humiliation. It is here that psychoanalytic theory intersects with the experience of being a caregiver—so much of the experience of that labor revolves around confronting others’, as well as one’s own, shame, to say nothing of physical illness and death.

¹⁷ Gibson-Graham (1996b) tells us that a feminist politics of partial identification insists on the in-essential nature of identity. Essentialized notions of “woman” amount to a kind of discursive violence that fixes the meaning of the category (here we may recall the way in which feminist theory and practice became aware of racial and class difference during the 1970s). Gibson-Graham also argues that essentialist representation forestalls the process of partial identification whose political possibilities frequently cut across these other fields of difference. (The example they supply in this text is how working class and managerial household economies in a coal mining community in Australia came to see themselves as allies in a struggle against the devastating practice to swing shift scheduling that affected all households). From their perspective, a feminist politics proceeds from the position of a negative “universal” in which all identities are understood as incomplete—that not all has been said, imagined, or identified with. This post-structural insight comes the closest to the new Lacanian conception of the ethical that I use here. As Derrida (1996) reminds us, an act is ethical only when its outcome is uncertain. As I have argued elsewhere (Byrne and Healy, 2006) the ethical subject manages this contingency differently because they experience this fundamental lack (how to allocate care, run a household, manage a firm, inhabit an identity) as a condition of partial identification and possibility rather than seeing it as a sign of failure. For Copjec (2002), it is the acceptance of indeterminacy, and the partiality and possibility that

it implies, which constitutes a “feminine” subject. For the New Lacanians the “feminine subject” is only one capable of a truly ethico-political act.