

CARE IN THE COMMUNITY ECONOMY: TOWARDS AN ALTERNATIVE
DEVELOPMENT OF HEALTH CARE

A Dissertation Presented

By

STEPHEN HEALY

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Department of Geosciences

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DEDICATION

To my father, who taught me the meaning of care.

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There are too many people for me to acknowledge, all of whom have contributed to my development as an academic, a thinker and a writer. All of whom through their attention and care have given this project its depth of meaning. Julie Graham's tireless commitment to my scholarly development takes shape in my mind either as a debt that cannot be repaid or as a gift that I must accept with as much grace as I can. I must give heartfelt thanks also to Richard Wilkie and Myrna Breitbart for their encouragement in this project over the years—challenges, suggestions and invitations to think differently that helped me on my way. I would also like to thank Rose Heyer for her support over the years, her clarity in expressing “the point” of this project when I could not see it. Thanks to Ken Byrne and Meredith Gray for tireless patience in editing previous drafts, clarifying my aims, and objectives. I would like to extend special thanks also to Yahya Madra—whose enthusiasm for our shared work and psychoanalysis proved indispensable. I should also like to thank my family for their support and encouragement. Many thanks also to Ceren Özselçuk, Joe Rebello, Becky Forest, Peter Tamas, Chizu Sato, Kenan Ercel, Maliha Safri, Anasuya Weil, Gabriella Delgado, Greg Horvath, Brian Bannon and other members of the Community Economy and Subjects of Economy seminars for the intellectual inputs that helped the development of my work. Finally, I would also like to take this opportunity to express my gratitude to my interviewees and friends. It is their insights that I am trying to express in these pages, however tentatively.

ABSTRACT

CARE IN THE COMMUNITY ECONOMY: TOWARDS AN ALTERNATIVE
DEVELOPMENT OF HEALTH CARE.

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The health care reform debate in the United States is defined by the choice between free market reform and a government-administered single payer alternative. Nearly half the population receives access to health care through government directed programs (e.g. Medicare) while the remainder is covered by private insurers. In spite of the current mix of allocation mechanisms advocates on both sides of the debate have argued for the superiority of one form over the other in controlling costs and constraining aggregate demand. Precisely because allocation is the focus of the debate, “health care” is conceived of as a cost incurred by businesses, individuals and/or the government. A miserly attitude prevails.

This dissertation aims at developing a new discursive context in which to politicize health care reform. I have used qualitative research techniques to explore the spaces in which health care is produced, allocated and consumed. The concept of the diverse/community economy, developed by J.K Gibson-Graham and the Community Economies Collective, provides us with a language for differentiating the economic landscape. This typology not only allows us to recognize the importance of informal caregivers in the economy of care but also to

recognize the different organizational forms, processes of exchange, ethical commitments in health care's "market sector."

A common theme has emerged from my interviews with informal care providers, physicians, community based health care institution administrators and alternative practitioners. All of these people spoke of their ethical commitment to care, how the practice of caregiving is deeply affecting. Interviewees recognized that caregiving was at moments a source of profound meaning while, at other times, it was a threat to their emotional and physical wellbeing. This dissertation concludes with an argument for thinking of health care "reform" as a process of development that focuses on the affective intensity of care and the ethical commitment of care providers. The aim of this development project is to produce supportive conditions for caregivers operating in both the formal and informal settings to be ethically engaged subjects.

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CHAPTER I

HEALTH CARE REFORM AS DEVELOPMENT

Introduction

This dissertation is an intervention into the politics of health care reform in the United States. The debate over health care reform has been a regular feature of the political landscape in the United States for nearly a century. The poles of this perennial debate is whether the United States should adopt a national health insurance system, as has been done elsewhere in the developed world, or whether the shortcomings of the present system simply reflect the fact that the provisioning of health care needs to be more fully subjected to the innovative and disciplinary logic of free market exchange. What is at stake in this debate, fundamentally, is whether access to health care is a right to be guaranteed by the state or is a commodity among other commodities. The initial question I would pose in this dissertation is why has this debate been continuously restaged without being resolved.

The answer that has ultimately suggested itself to me is that both sides of this debate share a common understanding of what health care is, where it takes place, who is involved and what their motivations are as patients or care providers. These fundamentally spatial assumptions—what, where and who—not only define the political economy but also delimit the range of possibilities for health care reform. Put simply, health care is understood to be something produced in hospitals and clinics using expert knowledge and expensive equipment. Patients are seen as consumers who, when released from financial constraints, will demand as much care as possible. Providers, seeking to maximize income, are imagined as only too happy to comply with this demand. The overall

effect of these initial assumptions is to create a representation of the economy of care governed by excessive demand and intrinsic scarcity. The rising cost of care as well as its declining quality, most famously documented by the Kohn *et al.* (1999), can be read as evidence that care is scarce relative to our demand for it. From this perspective the choice of “government vs. market” allocation of care becomes a choice of how we prefer to impose limits, by what means we will contain costs and constrain demand. Our choice is between two opposed forms of miserliness.

My ultimate aim is to create a spatial representation of the caregiving process, of being a patient or a provider, that is dispersed across the social landscape in hospitals and clinics but also in homes, churches and schools necessarily involving a diversity of actors—unpaid or informal caregivers, alternative medical practitioners, volunteers, public and community health workers, etc. From this perspective “scarcity,” as it is conceived in the health care reform debate, can be seen as a partial effect of an already impoverished conception of what care is, where it takes place, who is involved and why. Expanding the scope of our imagination of care has important implications for how we conceive of health care reform. While I am persuaded by the arguments that health care should be a right and that a government administered national health insurance policy might provide the most efficacious means of securing that right, this would only be one step. True health care reform would involve an examination of all the spaces where care is produced, the conditions under which it is produced, and how it is consumed.

Motivation

I have both personal and theoretical (political) motivations for writing on the topic of health care reform. My own experiences of being both a care provider and a patient along with the experiences of friends and family have deeply affected me as I have struggled to write on this topic. I have had friends express their rage at oncologists who disrespect the time of patients and their loved ones while providing treatment that extends not life but misery. I watched another friend care for an ailing parent struggling in isolation, without effective help from the Veteran's Administration, only to be overcome by despair. I have watched others perform palliative care for family members and friends and seen both caregiver and patient positively transformed by the process. I have received care from doctors at the University of Massachusetts Amherst, where I have been treated respectfully and seen for myself how skillful questioning and examination from providers has led to insights about my own well-being that were previously hidden to me. While the health care reform debate operates on a "policy level," most of us are continuously exposed to health care in our personal lives. It is important to make sense of our experiences as patient and provider since they are, perhaps, the origin of the frustrations, desires, fears, hopes, sadness and joy that we invest in health care and the occasional fervor of the health care reform debate.

Like many others I am also motivated by a concern for the large number of people in U.S. society for whom care is inaccessible, the forty five to sixty million people without insurance, the declining quality of care received by the indigent and the way that it reflects the emergence of a multi-tiered health care system (Pear 2003). The mainstream health care reform debate takes the allocation of

care as its general starting point, arguing over whether public or private (insurance) allocation of care achieves maximum care quality and accessibility while containing costs. Geographers and scholars from other disciplines have documented disparities in health care access in the U.S. in relation to race and (income) class. This literature paints an alarming picture of how these variations in access can have a catastrophic impact on the health and even the mortality of excluded populations. While I see the value in documenting variations in health care accessibility and quality my fear is that these facts are likely to be read in a way that re-enforces the power and centrality of “scarcity” as a master term governing the health care reform debate.

Disparities and Other Unmentionables

Wennberg’s *Atlas of Health Care* (1997) maps variations in health care spending in different regions of the United States. Some view the *Atlas* as a confirmation of Say’s law—per capita health care spending is greatest in areas with the highest concentration of doctors (Herzlinger 1997; Dranove 2000). It follows from this observation that the best way to contain care costs is to focus on cost control measures in areas that are highest in per capita spending. It should be pointed out that an equally plausible reaction to Wennberg’s atlas is to see in it evidence of the unequal and unjust distribution of care that reflect the historic effects of racial discrimination, etc.

Donald Berwick, founder of the Institute for Healthcare Innovation (IHI), remarked that the best indicators of someone’s life expectancy and overall health status in the United States remains the color of one’s skin and their income level (Kilborn 1998). Satcher and Fryer (2005) compare mortality rates by age group between blacks and whites living in the United States. While mortality rates have

gone down in all age cohorts in both populations there is a consistent gap between the two populations—when white mortality is set as a standard—that has persisted since 1960s.¹ The astonishing figure that made its way from their research to the popular press is that more than 80,000 African Americans die prematurely per year (Reuters 2005). Some argue that these disparities are an effect of certain populations making poorly-educated decisions about their own well-being and that increasing consumer “empowerment” will work to eliminate these disparities (Satel 2004). This argument, at best, leaves us with the proposition that these mortal disparities are a consequence of poor choices while leaving us to wonder why such choices are made. Moy, Dayton and Clancy (2005) confirm Satcher and Fryer’s finding through an analysis of the data generated by the congressionally mandated *National Health Care Disparities Report* published in 2004. This study examined multiple indicators of health care outcomes and quality from whether patients received counseling on smoking cessation to how effectively conditions like AIDS or breast cancer were treated. African Americans receive lower quality care in about two-thirds of twenty standard measurements than whites. The same pattern holds true for other minority populations with the exception of Asian and Pacific Islander populations who did slightly better than the white population on several indices.

¹ Standardized Mortality Ratios (SMRs) are used to determine the excess number of deaths in the African American Population. As life expectancy has improved mortality rates have risen in the upper age cohorts (75 to 84) and greater than 84. In the 1960s both of these values were negative for African Americans because they did not live long enough to produce a positive SMR. By 2000 this had changed to the point where there were 6,202 deaths in the black American population in excess of the white mortality standard. The value for the cohort above age 84 remains negative which means that black Americans, as a population, do not live long enough to produce a positive value in this age cohort.

Kawachi *et al.* (2005) offer a more complicated picture of accessibility. While they would agree with Smith (2005) and Eichner and Vladeck (2005) that racial discrimination has played a significant role in care access and health care outcomes (including these gross disparities in mortality) they would caution us against reducing health care disparities to racial discrimination alone. Income or class-based differences play a significant role in determining people's health, the accessibility of health care and the frequency of negative or positive outcomes.² They point out that while race is sometimes used as a proxy or even a code for class, it proves to be a poor correlate because 68 percent of the people who live below the poverty line are white.³ According to Kawachi *et al.* this has led some scholars to regard class as a confounding factor in collecting accurate statistics about racial disparities in care. Such a perspective militates against the common-sense recognition that

Low-income black Americans have more in common—as far as their incidence of heart disease is concerned—with low-income white Americans than with middle-class or affluent black Americans. (346)

For Kawachi *et al.* income-delineated class constitutes a separate system of difference that must be analyzed independent of race in order to understand how they both work to produce disparities. While class-based differences in health care outcomes are significant, they are difficult to track because

The U.S. government is one of the few developed Western nations that do not routinely report health statistics by class. For example,

² Here class refers to differences in income levels. The bulk of this dissertation will be concerned with a decidedly different notion of class that focuses on the variety of ways in which productive economic activity can be organized. This alternative notion of class is informed by a particular reading of Marxian economic theory.

³ They also note that race works very poorly as a category for tracking biological differences in health and well-being. As an example, while incidence of hypertension is very high among African Americans in the United States, it is very low among the people who currently reside in West Africa.

whereas long-term series are readily available on the U.S. black-white life expectancy gap, there is a dearth of corresponding data on trends in class disparities, whether measured by income, occupation, or educational attainment. (343)

In reflecting on why this is the case, they return to the insights of W.E.B. Dubois on the social meaning of race. According to Dubois, racism functions as a system of social identification that keeps the lowest class white man from identifying with African Americans in the same socio-economic stratum. The simple point Dubois was making was that the meaning of race was fixed in a particular way where blackness becomes associated with the static and whiteness with mobility.⁴ This set of associated meanings not only preempts any thought that might identify similarities across the lines of color, it also directly denies that socio-economic status (or class) has any fixed meaning, at least for whites.⁵

Kawachi *et al.* argue that DuBois's insights remain valid. Not only is it easier (statistically) to represent racial disparities in health care but it continues to be more acceptable to talk about racial rather than (income) class based health care disparities. Class-based disparities in health care outcomes are occasionally mentioned in the popular press but one courts accusations of "class warfare" in raising this issue (Krugman 2004). Kawachi *et al.* point out that, even if racial

⁴ Stuart Hall, in his address at Goldsmith College in London underscored the link between his assertion that "race functions like a language" and the evolution of DuBois' thinking on the subject of race (Jhally 1997).

⁵ As Kawachi *et al.* point out, this sentiment was repeated (off record) by Lyndon Johnson: I'll tell you what's at the bottom of it. If you can convince the lowest white man that's he's better than the best colored man, he won't notice you picking his pocket. Hell, give him somebody to look down on, and he'll empty his pockets for you. (349)

Kawachi *et al.* . point out that mid-twentieth century practices of the federal government's discriminatory administration of programs to ensure, housing, education, health care and the right to the collective organization of labor re-enforced the connection between whiteness and social mobility. According to Kawachi *et al.* ., it was also only with the legal successes of the civil rights movement in the 1960s that the public provision of social welfare began to lose some of its support amongst the white electorate.

disparities in health care quality, outcomes, etc. were to be addressed, the African American population in the U.S. will continue to have worse health care outcomes, life expectancy, etc. not because they are black but because they are, as a population, poor. One could read in the social prohibition against discussion of class a confirmation of Dubois' observations about the function of race—namely that it keeps us from thinking of how disparities in care access affect some segments of the population, both black and white.

Class- or income-based variations in care accessibility, quality and outcomes force us to directly confront the very question that U.S. society has been unable to answer for nearly a century. Is health care a commodity or a right and, if it is the latter, how do we define the content of that right? We may agree upon a collective right to emergency care after a car accident but is everyone who acquires lung cancer entitled to intensive and expensive chemotherapy? Is there a right to cosmetic surgery? These sorts of explicit questions (about the content of a right to care) inevitably involve us in a process of rationing care and with that comes the prospect of someone else deciding how much care we are entitled to. It should be kept in mind that government-directed programs of care—Medicare and Medicaid, the VA hospital system, etc.—already make decisions about what types of care will be paid for and which ones will not.

While the thought of an explicit practice of rationing care makes us uncomfortable, so does the alternative proposition that people should enjoy access to health care only in proportion to their ability to afford it. If one aspect of the American mythos is our mistrust of government another is our compassion and

generosity. Given the American character, it is difficult to say whether our compassion or our mistrust of government is stronger. However the question as to whether Americans will tolerate the allocation of care on the basis of ability to pay should not be posed in a speculative manner either. The present system of health care allocation—a mixture of private insurance, federally managed programs, and stop gap measures—already allocates care as if people deserve the care that they can afford. As epidemiologist Bruce Link observed,

It's as if we are creating disparities. It's almost as if it's transforming health, which used to be like fate, into a commodity. Like the distribution of BMWs or goat cheese. (Scott 2005)

My argument here is not that class-based disparities represent more accurately the source of health care accessibility or disparities in health care outcomes. Rather, it is my contention that class-based disparities remain unmentionable because they raise an unresolved question that is traumatic in nature. Most people would not want to deny care to someone who is suffering and no one can say they would want others to deny them care and comfort if they or someone they love is ill, injured or in pain. It is perhaps for this reason that the threat of excessive demand and the scarcity of care are not just common sense but a felt reality, which tells us we are facing a choice between explicit rationing (giving up some care we might be entitled to) or exclusion (denying care to those too poor to afford it). Given the impossible nature of this choice it becomes easier to understand why income-based notions of class remain unspoken and why the health care reform debate remains unresolved. While I respect the efforts of the scholars I have discussed here—it is my belief that bringing these disparities to light might unwittingly exacerbate rather than address the underlying fears and anxieties at the heart of the health care reform debate. Suffice it to say that these

attempts at bringing to light racial and class based disparities in care access and outcomes is a necessary but insufficient condition for transforming U.S. health care.

Health Care, Miserliness and Generosity

While this dissertation is both directed by personal experiences with the spaces in which care is produced and consumed and driven by a political commitment to addressing health care inequalities, there is an important way in which my dissertation parts company with the empiricism of the work detailed in the preceding section. The reason for this departure is that I wish to intervene in the health care reform debate from a different ontological and epistemological vantage point. Facts, including the ones described by Kawachi *et al.*, have a way of generating meanings that exceed the intentions of those who discover and author them. Disparities in health care access and the failing of the present system in which health care is produced, allocated and consumed can be read in a number of different ways that are, in no small part, shaped by our personal experiences in the health care system.

A foundational observation that structures this dissertation is that there is a libidinal economy of health care that structures and constrains the health care reform debate, as well as technical and practical efforts at reform. There is an economy of desire that is composed of our own suffering and our need for care as well as the identification and repulsion we feel in relation to the needs of others. The aim of this dissertation is to use both psychoanalytic and Marxian theory in order to understand how this libidinal economy intersects with both the work of caregiving and the ways we conceive of the health care reform debate. In my view, the everyday discourse in the popular press, talk shows, and magazines

provides us with evidence of how this libidinal economy of care functions. People take positions with respect to their own need for care and the needs of others in a number of common sense ways that express themselves as two opposed responses to health care, the needs of others and themselves. I call these positions “the miser” and “the caregiver.”

The Miser

In the summer of 2004 I turned on my radio to discover that the National Public Radio program *The Connection*, hosted by Dick Gordon, was discussing the role that the health care reform debate would play in the then upcoming presidential elections. The program featured two guests—the owner of a small auto-parts supply company in Ohio and a health care policy expert, Michael Sparer, from Columbia University. Both guests were discussing the failure of Managed Care Organizations (MCOs) to contain health care costs after a period of brief success in the mid 1990s and the likelihood that John Kerry’s (or John Edwards’) plans for a universal health care alternative would appeal to the American electorate.

Dick Gordon received a call from “Sonny” in North Carolina.

Dick: . . . To Kitty Hawk North Carolina, Sonny is up on the connection. Hi Sonny?

Sonny: Hi! You know I have a unique perspective to bring to this, at least one that hasn’t been talked about so far and that is, if you consider the fact that health care is not a fundamental right. You know for instance, in my situation my company pays an exorbitant amount of money for my coverage and I pay an exorbitant amount of money for my health care, I feel, and I don’t even receive any benefit from that until I’ve spent a thousand dollars in addition to what I’ve already spent to cover my deductible before they start paying 80 percent.

Dick: So, so what’s your point? Do we do away with insurance altogether?

Sonny: No. My point is, to look at from a different perspective. And you know, for instance, I'll go into a doctor's office and sit next to a Medicaid patient who's paying three dollars for a service that I am paying a hundred and fifty dollars for, after I've already paid my insurance deductible. And your guests have already talked about how there is a great deal of waste that's happening within the health care system itself. And I don't think that waste will be addressed by simply going to a universal health care system that's paid by universally by the government. I think it would contribute to the waste more than it would help. (*The Connection* August 23, 2004)

I see in Sonny's comment a different explanation as to why class and race are conflated. For Sonny the Medicaid recipients are the reason his own health care costs are so high. He could ask why his own premiums have gone up, why the cost of insurance has increasingly shifted from employer to employee or why the pharmaceutical industry has enjoyed record profits in the past decade. These competing explanations—and their political implications—are ignored in favor of an explanation that focuses on a distinct group of people getting something for nothing. Anxiety about the desires and needs of the others is, according to Jacques-Alain Miller (1994), the simplest expression of racist thinking—the belief that the “other” is enjoying something at your expense. What's crucial to note here is that the “race” in question are citizens who, because of their indigence, qualify for Medicaid. Sonny's analysis begs the question: are class and race separate ways of understanding social stratification and exclusion or is it possible that class difference can be the object of racist resentment?

The stakes associated with this question are high. The effect of this “racialized” understanding of social entitlement programs delimits the range of possible responses to the present shortcomings in health care. Constraining the enjoyment of free riders—for example, Utah's imposition of a new system of prohibitive co-payments to be made by Medicaid recipients—precludes a range of

alternative responses (Johnson and Ableson 2005). Satcher and Fryer (2005) argue that a widely accessible system of public and preventative health care that addresses indigent/minority communities would drive health care costs down by forestalling or preventing the development of expensive chronic disease. Yet such an argument would make no sense to someone coming from Sonny's perspective. How do we understand the attachment to a belief in the demands of a threatening other—one whose demands will overwhelm the health care system? I explore this question more fully in chapter II. Here, however, it is useful to note that Sonny's common sense is formalized by health care economists who represent both patients and providers as rational actors whose self-interests, in the absence of constraint, will cause health care costs to rise. In chapter II I argue that unless these fundamental assumptions are exposed and questioned, the health care reform debate is likely to remain unresolved.

Caregivers, Oprah Winfrey and Generous Souls

If Sonny's fear of an "other" who threatens his own enjoyment represents one end of the spectrum in the libidinal economy of care, then people who exhibit an intense drive to care for others, even at great expense to themselves, constitute the opposite end. *Oprah* is a successful advice and inspirational magazine that, strangely, spoke directly to my ambitions in this dissertation.⁶ My

⁶ Žižek once admitted that a children's story by Shell Silverstein did a better job of summarizing the aim of the psychoanalytic process than he ever could. I feel a similar embarrassment in admitting that Oprah's magazine allowed me to formalize some of my thoughts in relation to health care reform. I could feel in some ways that whatever I might say about caregivers is "already out there." For me it really is not a question of whether or not caregivers, especially those providing care in informal settings are visible but rather that insufficient theoretical attention has been paid to the caregiving subject—to what moves and sustains them, what material social, economic and emotional circumstances allow them to do what they do and what circumstances undermine them or dampen their capacities. Thus I see part of my dissertation's task is to engage with the common sense discourses of care but also to render them in unfamiliar ways so that we might take caregivers seriously as economic, ethical and political subjects.

sister had bought the December 2003 issue to pass the time while watching over my mother who in turn was caring for my father who was in the final throes of a rare and terminal lung ailment. I was flipping through the magazine when I came across a series of articles that seemed to directly address the topic of caregiving, albeit in the setting of the home rather than the clinic, with care performed by family members rather than professionals. That each of these articles was written by a woman is perhaps unsurprising given the target demographic of the magazine yet it was also symptomatic in terms of how notions of care and the concern for caregiving are evoked.

The first article that struck my attention was by the popular author Anne Patchett. "Caregiving, A Love story" recounted a personal narrative of a woman who had been raised by her grandmother and was now in a position to care for her in the twilight of her life. The article was almost sensual in its evocation of care, the loving attention that she paid to the bodily and mental well-being of her 92 year old grandmother. She describes how she gradually came to do the very things that her grandmother had once done for her—driving her around, keeping her company, and bathing her. The conclusion Patchett came to is that this experience reconfigured her understanding of love:

There was a time when I thought that Love was kissing, sweaty palms, desire. Now I know that love is this: sticking it out, the long haul. I pull her out of the tub, my chest and arms soaking and stand her on a towel to dry.

"What's this stuff?" she asks. When I tell her it's lotion, she says that's she's never heard of such a thing before. "But I like it," she says. "It's good."

I believe that liking lotion is a clear sign of life. I slather it on.
(Patchett 2003, 102)

Patchett's reflection underscores both the intimacy and intensity of a caregiving relationship and the poetics that are required to describe this relationship for the long haul.

Patchett's love story was surrounded on either side by other articles that reflected more broadly on the emotional dimensions of caregiving. In each of these articles it was not a question of the other's need or whether or not they were worth caring about, but rather a question of how to care—by what means does one attend to caring? "Be Excellent to Each Other" described the efforts of a temporary worker who tried to be engaged, caring and committed in each of the more than one hundred temporary positions she has had in the past fifteen years. Her care for others and attention to work functions as both an ethical maxim and means of enjoyment in much the same way that Patchett's caring was conceived of as both duty and pleasure. This was followed by yet another article "The Halo Effect" in which the author admitted that she felt compelled to be attentive to the needs of others for the sake of approval, and that she was being consumed by a need for validation. In quick succession we have the imperative to care, the pleasures of caring as well as the dangers of caring too much.

These three articles seemed to collectively suggest a different approach to the suffering and needs of others, posed as a series of questions and reflections. This discourse on caregiving is perhaps as familiar to us as Sonny's fear of the other's excessive demands. Collectively, the authors in *Oprah* constitute a counter-common sense where the needs of others are not to be feared but attended to. And with this different understanding of care comes an entirely different set of questions. What are my obligations to others? What satisfaction/recognition am I permitted from caring? How can I care effectively

without being overwhelmed or consumed by the needs of others or circumstances that militate against my efforts to be attentive? One is reminded of a fundamental insight that Freud articulated in *Beyond the Pleasure Principle*. Freud observed his nephew at play, throwing an object attached by a string out of his crib and then reeling it back. The boy seemed equally pleased when he pronounced that the object was away and when he found that it had returned to him through his efforts. Freud argues that this form of play is actually where the developing subject learns to work out his tension with the other, to achieve the correct distance/proximity from the other. The child creates through this play an understanding of the difference between the mother's physical presence and how she continues to be "there" even when she is physically absent. The name that he gave to this concept is *fort da*. What if these three articles about caring—investment in caring, avoiding narcissistic attachment, identifying with the other—constitute an adult version of *fort da*? In a sense, these authors are recounting how they learned to take pleasure in a relationship of care, to extend oneself to the other while avoiding the tendency to be consumed by the other or dependent upon their recognition. What if the object lesson in this popular magazine is that caring is about maintaining the proper distance/proximity to the other? Through this process we recognize that we have a relational debt to the other, an obligation to care, but that its symbolic significance (as onerous duty or source of joy and fulfillment) is not fixed but corresponds with our ability to manage the experience of caring.

This tension is at work even in someone like Sonny, who has, on the surface, adopted a suspicious and resentful relationship with the needs of others. We can see that he believes there must be limits to care or, at least, he fears that

another's care might come at his expense. This was, however, not the end of the story for him. Later in the program Dick brought on a woman who gave herself the name "Jane." Jane was currently in between jobs, lacked health insurance and had a lump in her breast that she refused to have checked out because she was afraid it would, in effect, render her unemployable or constitute a "pre-existing condition" that would prevent her from getting coverage in the future. In other words, her exclusion from health insurance—at the moment—prevented her from being proactive about her own well-being. The public policy expert Michael Sparer commented that this was both a tragic and familiar situation that many people find themselves in.

Dick Gordon then turned to Sonny, whom he had kept fortuitously on the line, and asked him, "What would you do with someone like Jane?" Sonny stammered and said, "Well, obviously this is unfair and there needs to be some guarantee of access to care in a situation like hers." He then went even further, stating that there should be provisions made to ensure that people have access to food and housing. In the space of a few minutes, Sonny went from arguing against the idea that care is not a right to arguing with equal conviction that it is or should be. How do we explain this radical inconsistency—the fear on the one hand that entitlement programs encourage laziness while, on the other, an earnest identification with "Jane's" suffering? How do we understand this split?

Seeing health care reform in relation to *fort da*—keeping the other's need for care at bay while also identifying with it—constitutes a decidedly different way of thinking about issues of exclusion from care or the need for health care reform. While Wennberg's mapping project and Kawachi's statistical analyses constitute one way to approach the issue of health care reform, taking stock of how the

libidinal economy informs the debate—measuring the “distance” between Sonny’s and Ann Patchett’s views of care—constitutes the beginning of a different approach. There has been a growing concern over the past thirty years within geography over the relationship between society and the subject. While the work of Foucault and other poststructural thinkers has played an important role in shaping geographic thought for some time, psychoanalytic insights have only recently come to the attention of geographers. The terms of this new theoretical encounter were summarized in an edited collection published in *Social and Cultural Geography*.

Psychoanalytic Geographies and Care

Interest in psychoanalysis as a theoretical approach to geography constitutes a minor trend within the discipline (Philo and Parr 2003). This is perhaps unsurprising since, at first blush, the two disciplines are incommensurate. While psychoanalysis (frequently conflated with psychology) is apparently confined to the scale of the body/individual, human geography is multi-scalar. Even when geographers are interested in the individual, or the body, their interest is usually focused on how this micro-scale relates to, shapes and is determined by social processes occurring on a larger scale.

Sibley (2003) nevertheless points at two parallels between psychoanalysis and geography. Initially he asserts that both are concerned with fixity and movement. Sibley speculates that one of the reasons movement played a decisive role in shaping the early psychoanalytic thought was that many of them, Sigmund Freud and Melanie Klein for example, were exiles. How might the experience of involuntary dislocation have affected their respective conceptualizations of trauma, the lost unity with the mother, etc.? Just as movement might have been

constitutive of psychoanalytic theory, geographers come to psychoanalysis through movement as well. Bondi (1999), for example, speaks of how her experience of being a patient eventually led her to use psychoanalysis in her theoretical work—a process she describes as a theoretical voyage or journey. One important implication of the way this movement towards psychoanalytic theory occurs is that the encounter is directed by individual experience, what theories or concepts in particular speak to them. Secondly, and with some caution Sibley, like Kingsbury (2003), notes that the psychoanalytic object (the unconscious) and the process of analysis are described in spatial terms. Sibley points out that the unconscious, far from being the idiosyncratic psychology of the individual, is the event horizon between a particular subject (individual) and the way that language conveys social meanings, values, prohibitions, pleasures, etc. For Lacan the neurotic's singular and idiosyncratic unconscious is rooted neither wholly in the individual nor in the society (as simple theories of ideology would have it). For example Sonny's "racist" anxieties about the Medicaid patient does not rest fully in his own experience nor is it an ideology that exists apart from himself.

For this reason Callard (2003) claims psychoanalysis has an ontology that is distinct not only from humanism and structuralism, but from versions of poststructuralism that still tend to regard the subject as a "position" that is determined by contingent circumstances in the larger social order. The figure of the mobius strip is used by Lacan to describe the relationship between structure (society), historically privileged by (post)structuralism, and agency (the individual),

privileged in the humanist tradition.⁷ Psychoanalysis represents a break from both of these traditions, recognizing the way in which each position is implicated in the other. According to Callard, it was Pile who first recognized the epistemic break offered by psychoanalysis in the early 1990s.

Pile demonstrated how psychoanalysis transforms lay understandings of external (social) and internal (individual) forces: “psychoanalytic theory, in its theories of the unconscious, describes how the social enters, constitutes and positions the individual” and, similarly “by showing that desire, fantasy and meaning are a (real) part of everyday life, it shows how the social is entered, constituted and positioned by individuals” (1993: 123). . .

and

Crucially for Pile, psychoanalysis can be used to address the relationship between power and language and, as a corollary to this, might be enormously useful for geography by virtue of its ability “to contribute to contemporary debates on the politics of identity, . . . to help articulate a politics of movement (and not merely position), [and] to respond to the demand for a politics of desire (1993, 136-137).”

In short Pile was the first to note that psychoanalysis offers a third position in the structure vs. agency debate in the late 1980s, a position to be found in the landscape of the unconscious. The conception of the unconscious—as a “space” where society (structure) and the agent (subject) turn into one another—had important implications for the clinical work of psychoanalysis. Social theorists are inclined to see a parallel in the analysis of social discourse. The approach I take in this dissertation is that the “health care reform debate” is like an unhappy analysand; it exists in a state of “stuckness.” The choice between collective allocation (universal health insurance) and a market-based alternative seems to replicate the “opposition” between structure and agency. The unresolved nature

⁷ A mobius strip can be formed by taking a strip of paper and forming it into a loop with a

of the health care reform debate provides us with an explanation for our unhappiness even as it is the cause of our suffering. My goal here, like that of the analyst, is to get this debate unstuck—to provide a different way of framing it—so that actual movement or resolution becomes a real possibility.

While the psychoanalytic alternative to agency and structure-centered analysis is inspiring to me, Callard concludes her essay with some cautionary remarks about psychoanalytic geographies, which deserve consideration. Her worry is that theorists move to leap to the political implications of psychoanalysis too hastily. The psychoanalytic process, according to Lacan, involves the identification of an Archimedean point, a place to lever the subject. For him, this process was never easy. Imagining that psychoanalysis offers a set of effective tools to remake the subject risks restoring a vision of the subject, agent or individual as a product of social discourse that can simply be re-inscribed. Her fear is that a selective use of psychoanalysis, its blending with other social theoretical traditions and its subordination to a political agenda risks taming the ontological implications of the unconscious. She urges us to remember that psychoanalysis is as much about inertia, impotence and repetition as it is about difference or transformation.

My initial response to Callard's caution is to readily assent to the truth of this. On some fundamental level it is not possible to "re-enscribe" the discourse around care so that the production, allocation and delivery of health care into a process that is always just, efficient and equitable. The nature of health care as a practice itself serves as a ready reminder of human limitations. It is space that will

single twist. The result is a topographic surface formed by a single continuous line that is at once

be permanently marked by fallibility, shortcoming and failure—if for no other reason than the suffering of the ill, the elderly and the injured cannot always be healed. Likewise, there is also something traumatic about being a care provider—exposure to the suffering, illness and death of another or identifying with a patient who has lost control of their bodily functions can induce a sense of shame or discomfort. Whether we are empathetic or callous towards the suffering of others, whether we ourselves benefit from the generous care of others or are denied it, suffering will remain. The real task here becomes one of how to bear that suffering rather than imagining that it can be transcended.

The work of the new Lacanian theorists—Renata Salecl, Joan Copjec, and Slavoj Žižek—offer us a psychoanalysis that is untamed precisely because they pay theoretical attention to the unpalatable aspects of psychoanalytic theory such as the “violence” and contingent nature of ethics, the possibility of failure, or even how Lacan used the Marquis De Sade in order to rethink Kant. Copjec (1995), for instance, sees in the figure of Antigone a model of ethical action even though her ethical act—insisting upon the burial of her cousins—results in both her transformation as a subject and the physical death of her body. Zupan i (2004) comes to this same conclusion by tracing Lacan’s peculiar reading of Kant (and Sade)—in order to show that even sadomasochism could be seen to conform to the Kantian categorical imperative (or golden rule). This reading of the ethical empties it of its normative connotation, allowing it to exist as an empty signifier. Psychoanalysis, from a new Lacanian perspective, intersects with the ethical and the political precisely because it provides us with a language to explain how the

the top and bottom edge of the surface.

ethical act transforms (or destroys) the bearer and how the shifts in perspective that accompany this transformation can feel like a violent or inconsistent lurch. The question we are left with is whether this same “lurching” effect can be produced or felt at the scale of political discourse.

When we first heard Sonny, his thinking was fixed in relation to limits—the impossibility of meeting all demands of an anonymous mass of Medicaid recipients. In the second moment he saw both the possibility and indeed the necessity of meeting the care needs of a suffering individual, “Jane.” What if this is a metaphor for how we should be thinking about health care and its reform? Currently the health care reform debate is marked by its irresolvable/impossible nature. What if what is required is that we perceive the economy of health care from a different vantage point? Adopting a different perspective on the economy of care would not require that we reject Sonny’s insistence that there are limits to care because, of course, there are. On the other hand what if we were to have a conception of care that allowed us to take seriously the experience that Ann Patchett was describing in economic terms—the joy and fulfillment of care, the specific concern with attention to and fulfillment in one’s duty to the other? What if, first and foremost, we had a way of approaching health care reform that was attentive to the needs of the people who were performing care? What if care as a productive economic activity got as much attention (from this perspective) as the allocation of care? If we were able to answer these questions we would be in a position to understand what is required for caregivers to perform and be transformed by their duties as caregivers. Health care reform would then revolve around the question of what set of measures should we take and what sort of experiments we should conduct so that the capacity to act ethically in relation to

care is maximized. Posing and answering this question would require us to depart from discourse of reform fixated on limits, economization, scarcity and mistrust and explore, however tenuously, a new conception of the economy of care that, while acknowledging limits, is oriented in relation to the possible.

Diverse and Community Economies

A central premise that informs this dissertation is that enacting a new politics of health care reform requires a new conceptualization of economy. The present discourse of health care reform—in both its political and “policy” incarnations—is fixated on the question of allocation in the face of certain scarcity. Just as the central fact of scarcity tells Sonny that “universal health care” will only make things worse, we are also told—in both the academic and popular press—that General Motors is facing Chapter Eleven because of out-of-control health care costs. In all probability, pointing out that GM’s executive pension liabilities annually exceed their layout for health insurance risks the same charge of “class warfare” that Kawachi *et al.* court in their analysis.

In the same way that the process of economic development has been subordinated by the imperative to attract, and retain capital investment—and to keep local or national industries competitive—health care costs, whether they are born directly or indirectly through taxation, must not deprive enterprises of the capital they need in order to survive. In this vision we can have a growing economy or social welfare, a competitive automobile industry or health care, but not both. Ironically, the whole point of attracting or retaining “growth sectors” like Information Technology or shoring up the U.S. auto industry is the expectation that these are sectors that provide both a tax base and quality jobs (Bartlett and Steele 1998). For a whole host of reasons, “quality jobs” has come to mean

occupations that provide fringe compensation including health insurance. Thus, the very set of institutions that are imagined to engender the conditions for social well-being and access to health care are also imagined to have a need for and claim upon social resources in order to reproduce themselves. It is at this point that I would like to pose a “what if” question: what if what we have here are not competing claims over scarce social wealth that pit health care against economic growth, but rather a rarefied conception of where wealth comes from? What if conflating a scarcity of care with a scarcity of capital—or an overabundance of claims upon capital—is precisely what engenders “racist” thinking in people like Sonny? What if there are sources of potential, of the work of care, whose importance we do not appreciate because of how we think about the economy?

Much of this dissertation deals with the results of qualitative research I have done with health care providers operating in a variety of spaces and social conditions. Turning aside from the perennial question of allocation I wondered if there were political and ethical dimensions of health care reform that we could consider if the full range of actors and spaces where care is produced was taken into account.

In the course of pursuing my doctoral research I was involved with a collaborative research project, the Rethinking Economy Project (REP), which was informed by the theoretical work of J.K. Gibson-Graham (1996) and the Community Economies Collective (2001a, 2001b).⁸ The goal of this research project was to free the process of regional economic development from a constrained imagination that revolves around identifying growth sectors of the

⁸ Funded by the National Science Foundation grant no. BCS-9819138.

economy—preferably in manufacturing—and then figuring out a way of making a region an attractive location for direct investment, usually through tax incremental financing or other forms of inducements.

In place of this impoverished imagination, the REP's initial goal was to replace this scarcity-based discourse of development, with its singular focus on capitalist firms operating in the market sector, with a new economic ontology that was fundamentally diverse in its nature. If the economy is thought of as a process of producing, distributing and consuming goods and services then economic activity takes place in households and other community locations as well as in firms. As Gibson-Graham (2003c) has pointed out, feminist theorists and activists have long been engaged in restoring the household as a visible site of productive economic activity. In Gibson-Graham's view there is a feminist politics of economy beyond ensuring the "visibility" of the household, a politics that recognizes the economy is heterogeneous in all of its dimensions. Drawing upon a theoretically eclectic combination of Marxian and feminist theory, as well as the work of economic sociologists, geographers, and anthropologists, the goal of the REP was to use qualitative research to substantiate the claim that every economy around the world is marked by a fundamental diversity in all of its dimensions with the moments of production, exchange, compensation, allocation, etc. constituting what we have come to call the "diverse economy."

This sense of the economy as diverse is, in a sense, already part of how we commonly understand health care. Hospitals, for example, are run as non-profits or for profit corporations, with the former being the dominant form (Dranove 1999). Likewise, access to health care (allocation) is organized in a diversity of ways: through direct government provisioning (e.g., the V.A. hospital system),

through public and privately administered insurance. This is, however, only the tip of the iceberg. Reading through the lens of the diverse economy, one can see that caring labor is provided by friends and family members as unpaid labor, given freely as a gift or out of a sense of obligation. Apart from involving both paid and unpaid labor the health care economy is diverse in other dimensions as well.

While some caregivers work as wage employees, others are organized as independent care providers or into worker collectives. These later organizational forms involve a completely different structure of governance in which the individuals and members of the collective who produce social wealth are also its first receivers.

The point, however, is not simply to render the health care economy visible in all of its diversity. Rather this is a first step towards an alternative politics of health care reform. Foremost, situating health care in the diverse economy changes the object that we are reforming. It is no longer a question of how to pay for care provided by physicians and hospitals but rather how we might rearrange all the paid and unpaid elements of the care economy in order to meet the needs of patients and the public as a whole. Rather than a politics of scarcity and restraint, the diverse economy allows us to imagine health care reform in relation to connection, possibility and articulation. In place of an economics of scarcity, there is a politics of possibility.

Chapter Outline

The remainder of this dissertation is divided into seven chapters. Chapter II addresses the first objective of the dissertation by tracing the political and economic history of health care in the United States in order to produce a psychoanalytic reading of the health care reform debate. I will argue that both free

market and single payer health care reform alternatives are fantasies conceived within a capitalocentric symbolic order and united by their common belief in scarcity. It is through this shared belief in scarcity that health care reform is reduced to the process of disciplining of both patient and provider, constraining their “enjoyment.”

Chapter III interrupts this intractable health care reform debate by means of feminist theory. Both sides of the dominant health care reform discourse are concerned with cost containment in the market sector—conflating health care produced in the market context with society’s total capacity to produce care. As feminist theorists have pointed out, however, a very large amount of health care is produced in households and community settings outside the market. This feminist interruption creates a momentary break in the stream of health care discourse. On the basis of this interruption I intend to pursue my second objective of resituating health care within the context of the diverse economy—suggesting the full array of actors, spaces, antagonisms and relationships that compose the health care sector in its entirety.

Following the agenda established in chapter III, chapter IV uses qualitative research to resituate health care within the context of the community economy. I begin by looking at care produced by informal unpaid care providers operating in the household and community settings. I then explore both the affective intensity of care and how being an informal caregiver can be either a process of subjectivation and positive transformation or can become the basis for psychic or even physical dissolution. Given these radically divergent possibilities the caregiver’s concern is to negotiate the affective intensity of the space of care without being destroyed by it. In turn, their ability to do so must be situated

within the larger set of social and economic circumstances in which the caring labor is performed, including the class process conditions.

Chapter V examines independent (self-employed) caregivers who provide alternative or complementary forms of care. Each of these caregivers speaks of the way in which complementary medicine reconfigures the space of caring as a partnership between patient and provider. For this care to work effectively the patient must become an active partner in the process of creating their own well-being just as providers are called to be more intimately involved with people in their care. The intensity of this collaboration creates a number of ethical dilemmas for independent care providers, but each one of my interviewees spoke of the difficulty in determining how much to charge for their services. I conclude this chapter by considering how their involvement in an independent class process allows them to address this ethical dilemma.

Chapter VI explores qualitative research interviews that I conducted with physicians, nurses and other care providers operating in the allopathic and formal “capitalist” health care sectors. Each one of these interviewees was very critical of the productive environment in which they were involved, how management decisions were made and the quality of care services that were produced. Using the work of DeMartino (2003) I suggest that each of them identified moments of productive, appropriative or distributive injustice in the environments where they worked and that each of them was committed to different courses of action to address the inequities.

Chapter VII explores interviews I conducted with administrators of community health centers, elder service centers and critical access hospitals. Each of the people I interviewed saw their work in these institutions embedded in and related

to the community they served. This relationship between care-giving institutions and the communities they served was, in their view, positively enabled by creating circumstances in which they were accountable to the community. At the same time each of these interviewees saw how the work in these local institutions could be enabled by a financial commitment from state and other forms of social support from the community on a voluntary basis.

The chapter VIII concludes by examining the class dimensions of community economy theory allow us to imagine an alternative politics of health care reform. Through the lens of class analysis, a vision of health care's natural scarcity is replaced with a politicized struggle over surplus. In this way the class analytic intervention traverses the fantasy of health care reform. Surplus analysis allows us to re-imagine the politics of health care reform in relation to both the conditions under which health care is produced and the ways that health care relates to the greater community economy of which it is a part. In place of health care's subordination to other productive industries, the community economy perspective allows us to see its hidden connections and economic and social potentiality.

CHAPTER II

HEALTH CARE AND THE FANTASIES OF REFORM

Introduction

The people of the United States have been engaged in debate over the health care reform with varying degrees of intensity since the early 1900s. Each time this debate resurfaces, it is framed in relation to a looming crisis. In 2003, the signs of this crisis—rising medical costs, the growing number of people who lack access to care, labor strife over the retention of health care benefits, growing disparities in the accessibility and quality of care—could be found almost daily in newspapers across the country.

These are the headlines from U.S. health politics in 2003. If they seem familiar, however, you are experiencing what Yogi Berra famously called “dèjà vu all over again.” Indeed, these headlines could just as easily have been written about the health care system in 1993 or, in many respects, in 1973. Simply update the numbers for the uninsured and national health spending, and the newspapers could run the same stories. (Oberlander 2003, W3-391)

The general consensus is that something must be done to resolve the crisis, that the health care system is reaching a breaking point and that U.S. citizens will not stand for things to remain as they are.

The terms of the health care reform debate are marked by a particular regularity, pitting those who advocate free market reform against those who would prefer a government-run, “universal” alternative that would guarantee access to care as a right. Contemporary advocates of the pro-market position (e.g. Dranove 2000; Herzlinger 1997) argue that government involvement in care allocation and insurance is inherently inefficient. From this perspective, the more access to health care resembles a free market, the more competition and innovation will work to make quality care accessible and affordable. Moreover, many would argue it is

the presence of well-meaning but meddlesome entitlement programs and government interference that account for the rising cost of health because they interfere with the natural workings of market exchange.

People who advocate for health as a right and for government involvement in care allocation would argue that the current system, dominated by employer-based private insurance, leaves many people without access to regular care. They would point to the 45 million people who are currently uninsured as proof of a categorical failure of market-based allocation of insurance. They might also point out that there are considerable discrepancies in the quality of health care provided in this country, especially access to regular and preventative health care, as we saw in the introductory chapter (Anders 1996; Kawachi *et al.* 2005). One consequence of this is that economically-marginalized people often end up developing chronic or acute conditions, which translate into expenses that might have been avoided if preventative care was accessible by right. Discrepancies in the accessibility and quality of care ultimately make health care more expensive while adversely affecting the productivity and well-being of the whole society (Kawachi and Kennedy 2002).

Dukakis (2004) observes that this particular debate over health care reform has been a feature of the U.S. political landscape since the era of Theodore Roosevelt, when he proposed that the U.S. follow Germany's lead in establishing a government system to secure universal access to modern medicine. Dukakis argues that the debate over health care reform from the early twentieth century bears an uncanny resemblance to debate in the 1950s, 1960s, 1970s, 1990s and today. Each time the debate comes to the fore politically, the nominal issue has been whether health care is a "right" or a "commodity." What one cannot miss

about the debate is that it focuses almost exclusively on the choice between two contending mechanisms for allocating health care.

One could make the case that the opponents of national health insurance (and of conceiving of health care as a “right”) have won the debate simply because things have not changed. Health care access has not become a right 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 way that health care allocation has evolved over the past fifty years complicates the picture. 60 percent of the population secures access to care by purchasing private insurance or obtaining it through an employer as a form of compensation, though that number is expected to shrink to 50 percent within the next seven years (Ableson 2005; Pear 2004; 2005). In contrast, the government’s role in ensuring access to care has steadily expanded over the past half century. As Dukakis pointed out, the establishment of the Veterans Administration health care system at the end of World War II guarantees veterans access to health care regardless of their ability to pay. In the 1960s legislation establishing Medicaid and Medicare was passed to provide access to health care for other vulnerable populations—the elderly, the disabled and the indigent. Finally in the 1990s, in the wake of Clinton’s failed health care reform initiatives, state programs were put into place to ensure that children of families who were too wealthy to qualify for Medicaid were covered by some form of social insurance. Thus, Federal and state-managed programs have come to serve as a supplementary form of social insurance for those who are too old to work, too young, too poor, or too infirm. Though the government’s role in insuring these “exceptional” populations has expanded, the formal ratification of

health care as a universal “right” of citizenship has been struck down every time it has been brought up.

The temptation here is to make yet another argument as to why a national health insurance scheme is both morally and practically superior as a way to allocate health care. My aim is to resist this impulse in favor of asking another set of questions. Why is it that the health care reform debate is continuously restaged in these terms without being resolved once and for all? While the idea of making health care a right has been rejected in the political arena every time it has been proposed, why has the state become progressively more involved in granting access to care? Why is it that widespread public support for Clinton’s proposal for health care reform evaporated so quickly (Kirsch 2003; McKenzie 1994)? The debate over health care reform has existed for nearly a century in a state of deadlock where the apparent necessity of reform is matched only by our inability to decide how to fix the problem, though we seem to be “fixing” it along the way. We cannot settle on an answer to this question nor, apparently, can we turn away from it.

Patchwork Systems, Too Many Explanations, Endless Recriminations

There have been many attempts to understand why the health care reform debate has ended up in a state of impasse. Many of these explanations have focused on the peculiar ideological climate in the United States and/or the development of powerful, entrenched interests that align themselves against any sort of efforts at reform. Others have sought to explain the present impasse by looking at the way that organized labor—the driving force behind the creation of national health systems in other countries—has failed to behave in this way in the U.S. context. Some people see in this mix of public and private systems a

complexity that creates so many entrenched interests that it would be impossible to reform health care allocation. Reviewing these different explanations reveals a surplus of compelling reasons why the U.S. cannot establish health care as a right. As Žižek asserts, such a radical redefinition of care, from a psychoanalytic perspective, constitutes a passage to the act (Butler, Laclau and Žižek 2000). The act, from his perspective is nothing less than a radical move that would constitute a new social problematic in relation to care beyond the terms of this stalemated debate.

Explanation One: Partisan Rancor

Engel (2002) focuses on the role of ideological conflict in creating the deadlock between those who advocate a rational universal health care and those who insist that health care be left to the free market. By exploring the earliest efforts at reform, he argues, like Dukakis, that the ideological positions taken in this debate have been remarkably consistent throughout the twentieth century. The Committee on the Cost of Medical Care (CCMC), commissioned in 1906, found that there were significant disparities in access to care that broke down along the lines of socio-economic status, with the lowest quintile using medical services far less than the wealthier segments. Their proposal to correct this inequity was

to forge a health system out of the disparate and independent components of medical care in the United States. Such a system was predicated on the creation of ‘community health centers,’ which would house inpatient and outpatient facilities, a pharmacy, clinics, and nursing and dental care. (Engel 2002, 38)

The idea was that these community health centers would operate on an economy of scale—specifically a reduction of administrative overhead—without compromising the intimacy of doctor-patient relations. They were to be paid for by a universal income tax. In short, the belief was that universal access to care was

of such importance that it should exist as a public commitment. What is astonishing is that both the problems the CCMC was trying to address and their proposed solution are strikingly similar to how progressive reformers frame the issue today (e.g. Sagar 2003; Goyer *et al.* 2004).

The solution proffered by the CCMC sounds familiar and the scorn with which it was met bears an uncanny resemblance to the standard objections raised against government run universal health care to this day. At the time, the principal voice of opposition was the head of the American Medical Association (AMA), Morris Fishbein, who insisted that any sort of collectivization of risk led down the path to socialism and the ruination of the American moral fiber. In his forty-year tenure as the head of the AMA, Fishbein was unrelenting in his opposition. He even maintained his resistance to private insurance and sickness funds as forms of “collectivism” long after the majority of AMA members accepted them as a necessary evil (Engel 2002, 110).

Fishbein might have been extreme in his beliefs, but fears about government interference in the patient-doctor relationship have persisted to this day. These fears played a prominent role in a series of television ads paid for by the National Federation of Independent Businesses, which was credited with undermining popular support for the Clinton health care plan (Kirsch 2003; West 1996; Goldstein 2001). The ads featured a couple, Harry and Louise, reading a newspaper and discussing the health care crisis over breakfast (see figure 2.1).⁹

⁹ While the kitchen and the actors may be the same, this particular image comes from an ad where Harry and Louise are discussing the benefits of stem cell cloning nearly ten years later in 2002.



Figure 2.1: Harry and Louise

While they both agreed that something must be done about health care crisis, Harry's assertion that a "government program doesn't make sense" was met with a nod and a knowing "mmhmm" by his wife Louise. According to Kirsch, the ad worked, not by suggesting that the government plan would fail for some definite reason, but by simply raising doubts about whether or not it is wise to allow the state to come between you and your physician.

Similar arguments against a single payer system are deployed in the contemporary context, as illustrated, for example, by George Bush's responses during the second and third presidential debates in October 2004 to the Kerry-Edwards call for health care reform:

He said he's going to have a novel health care plan. You know what it is? The federal government is going to run it. It's the largest increase in federal government health care ever. And it fits with his philosophy. That's why I told you about the award he won from the *National Journal*. That's what liberals do. They create government-sponsored health care. Maybe you think that makes sense. I don't. Government-sponsored health care would lead to rationing. It would ruin the quality of health care in America. (Bush 2004b)

It is ironic that Bush made this argument because the Kerry-Edwards proposal, like the Clinton proposal before it, depended upon cooperation between the federal government and private insurers. Bush's argument echoes Fishbein's sentiments. The fundamental problem, from his perspective, is that any type of insurance (both government and private) introduces a third party payer (someone other than

the patient) and releases the patient from any need to be responsible in their demand for health care. It is this lack of personal responsibility, combined with frivolous lawsuits that, according to President Bush, drive up health care costs. From this perspective, guaranteeing a right to care will only make things worse.

Bush's alternative relies on the gradual introduction of social measures that would create the conditions for personal financial responsibility with respect to health care. While the Medicare Modernization Act of 2003 contained provisions for the expansion of pilot programs for individual Health Savings Accounts, Bush's alternative remains largely in its infancy. According to advocates, these tax-free medical savings accounts will encourage personal responsibility and free-market competition, reforming health care fundamentally. To date, however, this extreme free-market proposal has amounted to little more than a nominal gesture. In contrast, the most decisive reform undertaken by the present administration has been, ironically, to expand Medicare. The question becomes, how can we reconcile this ideological suspicion of government intervention with the steady expansion of the state's role in allocating care regardless of the balance of political power in Congress or which party resides in the White House?

Explanation Two: Labor's Reluctance

Gottschalk (2000a) examines a peculiarity in U.S. labor history—the ambivalence that labor has exhibited towards the idea of universal health care. Access to health care through private insurance provided by employers became a regular feature of unionized wage employment in the manufacturing sector following WWII. During the war, health insurance became a standard non-wage form of compensation in order to attract and retain labor in an environment where the federal government controlled wages. When the war ended, businesses in

many enterprises began to adopt this practice. There are definite advantages to providing employees with non-wage compensation, like insurance, that accrue to both employers and workers. Employers can write off the expenses associated with providing health care for their workers, while for workers health insurance as fringe is a form of untaxed compensation (Gottschalk 2000a; Kleinke 2001). As an important part of the capital-labor accord, this “private welfare state” of employer-provided health insurance harmonized the interests of unions and employers; the well-being of employees literally became attached to the success of their employers.¹⁰ While most unions were politically committed to the creation of a national health insurance system, collective bargaining revolved around the progressive expansion of insurance benefits allocated through the “private welfare state” (Bluestone and Harrison 1982).

In the late 1970s many labor organizations did an abrupt “about-face,” abandoning support for the Kennedy-Mills bill that would have created a national health system in favor of “employer mandate” legislation that would compel workplaces to provide insurance. This is a curious development, since labor argued against Nixon’s employer mandate proposal, stating that such a system

¹⁰ Gottschalk (2000b) points out that there were two aspects of U.S. labor law that created conditions for organized labor to be invested in preserving the system of the private welfare state. While the Taft-Hartley act of 1947 is most famous for the way that it restricts the rights of unions to organize it also contained provisions that allowed unions to maintain health and welfare trust funds. At their height, these union-administered plans covered more than half the population of organized labor and their dependents. Labor was largely unconcerned with the fate of these funds through the 1970s, should a national health insurance system be adopted. Gradually labor’s position was realigned in a way that reflected their literal investment in the private welfare state. Gottschalk suggests that it was for this reason that labor made sure that the Employee Retirement and Income Security Act (ERISA), passed in 1974, exempted these plans from any sort of state or federal regulation. During the 1980s the preservation of these funds—which were by then in financial crisis—became more important to particular unions than continued support of efforts to establish national health insurance. Further, these ERISA-exempt health and wellness funds were notorious for their discriminatory coverage, including the withdrawal of benefits for those who contracted HIV (243).

“would perpetuate many of the inequities of the existing job-based system of health benefits” (Gottschalk 2000b, 235).

The critical question Gottschalk asks is why labor would embrace a plan that more firmly connected health insurance to employment at a moment in history when unemployment was high and labor was in its weakest position since WWII?

Her answer revolves around the way labor increasingly came to see entitlement programs directed by the government as a burden imposed upon U.S. businesses. Labor leaders argued that expanding an existing system of employment-based insurance by mandate would eliminate the ability of some businesses to free ride while creating conditions that would allow health care costs to be contained through competition amongst private insurance firms.¹¹ The rationale was that health care costs were the cause of American businesses’ failure to compete in the international market place. “Increasingly, the health care issue was subsumed in questions of economic performance” (Gottschalk 2000b, 237). As the unemployment rate approached 10 percent under the Ford administration, labor’s insistence on the preservation of the private welfare state became even more pronounced. Rather than seeing the macro-economic crisis of the early 1970s as an opportunity to make common cause with the rest of society in advocating for a universal health insurance, labor abandoned this political commitment.

The irony was that labor’s continued embrace of private insurance and its concern with the “competitiveness of American industry” helped, ultimately, to facilitate the shift of health care costs from employers to employees who,

increasingly, pay a larger share. By 1991 it was estimated that the average American family was paying two-thirds of the sixty-five hundred dollars spent on health care annually—and yet most of organized labor, along with the Clinton administration, continued to insist that health care costs were primarily hurting U.S. employers (Gottschalk 2000b, 245). As the practice of shifting the costs of health care from employer to employee accelerated, benefits became a central feature of labor-management antagonism. During the 1990s two-thirds of all labor-management disputes involved health care benefits as the principal issue (Gottschalk 2000a).¹²

Clearly U.S. labor has failed to play the role it has played in other social democratic countries where a national health insurance system has been established. Precisely because each individual union is struggling to preserve access to care through a private welfare state, health care is tied to the economic viability of the enterprise (and the economy as a whole). Given the long downturn described by Cox (2004), among many others, it is unsurprising that the diminishing fortunes of U.S. manufacturers and enterprises in other sectors have produced a politics of concession.

¹¹ The idea here is that the self-interest of businesses would force competition amongst private insurers to provide benefits at the lowest possible cost.

¹² At same time there was a tectonic shift in the composition of the U.S. labor force that intensified and directed the nature of this conflict; a full time unionized labor force was being replaced by a contingent, non-unionized work force. As Gottschalk points out, these new workers were subject to cost-shifting practices even more intensely, if they were offered benefits at all. This brings another irony to light. Organized labor's initial argument against the employer mandate system focused on the belief that it

would reshape the labor market in undesirable ways by providing employers with an incentive to replace full-time workers with part-timers, to rely more on compulsory over time rather than hire new workers, all in an effort to avoid health insurance. (Gottschalk 2000b, 237)

It turns out that labor's embrace of the "employer mandate" as a pragmatic compromise ended up facilitating precisely these developments in the U.S. labor market.

Explanation Three: Complexity Itself

John Kleinke, economist and insurance industry insider, argues that it is simply the complexity of the U.S. health care system that prevents any thoroughgoing reform.

Because of a unique and difficult moment in our nation's history [WWII], our health system was slapped on top of our employment system, with the government picking up the enormous slack for most who fell outside of that system. And so it began. The imposition of the nation's employers, insurance companies, legislators, lawyers, investment bankers, insurance brokers, and countless other corporate and regulatory middlemen into the financing and delivery of medical care is the source of the fundamental structural problems that cripple health care in this country. (Kleinke 2001, 2)

Kleinke's argument is that the U.S. has evolved a set of parallel systems for allocating health care and that a whole set of entrenched interests have attached themselves to these systems, driving up cost. His conclusion is that nothing short of a catastrophe would create the conditions for a thoroughgoing reorganization of health care.

Others have noted that the complexity of the system produces a situation where cost control in one area leads to price increases (profitability) in another (Finkler 2002). Hospital costs grew at double-digit rates throughout the 1980s until Managed Care Organizations (MCOs) were able to effectively contain costs through a variety of means. By the late 1990s MCO premiums grew at double-digit rates in part because of a changing regulatory climate that decreased their ability to bargain with hospitals and pharmaceutical firms.

Conflicting ideologies, the peculiar and quixotic nature of the U.S. labor movement, and the complexity of entrenched interests are just some of the many explanations for why the health care debate remains unresolved or why it seems

impossible to resolve. Each of these explanations tells a different story as to why universal health care has not come to prevail in the United States and why the system of mixed allocation has become an increasingly entrenched feature of the health care landscape. Both “free market” and “universal health care” advocates would agree with the National Academy of Science’s assertion that “the health care delivery system is incapable of meeting the present, let alone the future, needs of the American public” (Corrigan *et al.* 2003; Welch 2003).

The difficulty with these different perspectives is not that they are unconvincing, but, on the contrary, that they are all compelling. All of these explanations offer some reason as to why we have failed to decide, why the U.S. health care system exists in a deadlocked middle ground and how this indecision—as everyone agrees—is only making things worse. What if this seeming paralysis needs to be explained theoretically? What if our collective indecision is not just a function of the difficulty of the choice, but of a familiarity with and “enjoyment” in not deciding?

Fantasy as an Alternative Explanation

Discourse and the Symbolic Order

In this chapter I will argue that the health care debate should not be viewed as a rational dispute between the proponents of two alternatives. Rather this “debate” is better understood, with the help of Lacanian psychoanalytic theory, as the clash of two contending versions of a fantasy articulated within the terrain of a single discourse. By entering into the health care reform debate we become subjects who espouse particular beliefs about what is to be done. In the process, the participants become subjected to the terms within which this debate has been historically conceived—for instance, its nearly exclusive focus on the relative

merits of market vs. governmental allocation of health care resources. The two principal subject positions within the health care reform debate are united by a common symbolic order. They share the same ideas about the nature of the individual, society, the economy and their respective relations to health care and its role in producing well-being.

The Lacanian concept of discourse shares much in common with thinking of Michel Foucault. It is worth laying out these similarities since Foucault's work has had a wide-ranging impact on social inquiry in all fields over the past two decades. For Foucault, discourse functions to produce contours of "reality" by means of regularities and exclusions that define what it is possible to say and what is inconceivable. Foucault (e.g., 1977) points to the way certain concepts (e.g., who is a prisoner or a patient) become a governing regularity in speech and in relation to daily operations and procedures of institutions (e.g., prisons and hospitals). The language of conceptual regularities becomes inseparable from the "institutional reality" that it describes. Foucault's use of the term "discourse" is meant to capture the materiality of what has been variously referred to as the symbolic order, sign systems, language. While regularities define subjects and institutions, exclusions function as the limit of any discourse. For instance, the health care reform debate focuses on particular spaces and actors—doctors, hospitals and patients—in defining the health care sector and its crisis while excluding other spaces and actors such as family caregivers working in the space of the home.

This capacity of discourse to structure our conception of reality through regularities and exclusions has led some to characterize Foucault's work as a carceral theory of subjection. Rather than the soul being a prisoner of the body,

the body is a prisoner of the language that constructs social reality (Macherey 2004, 11). From this perspective it would appear that Foucault is saying that everyone is caught in the web of power/knowledge and that there is no escape, no progressive or liberatory use of knowledge. For this reason, Fraser (1985) dismisses Foucault's theoretical work as an apology for conservatism. Others regard Foucault's insistence that anyone espousing a "humane" use of power should be held to account for past deceits and that this accounting is the basis for an alternative politics (Blacker 1998).

For Foucault, efforts at reform or social transformation are confrontations with the dominant discourse. In Foucault's vision, politics is principally an enterprise of transforming the meaning of institutional power by shifting the regularities and exclusions that govern any discourse. His practice of genealogy traces the history of regularities and exclusions that define a field—criminology, for instances—creating in his reader an awareness of how the natural and self-evident is actually a product of chance utterance, repetition, and the accretion of disciplinary practice. Could we not say, then, as Blacker (1998) does, that Foucault's aim is to unsettle his readers, to create for them an uncanny moment where self-evident certainties are thrown into doubt?

It is Foucault's wish to generate this "unsettling effect" through genealogy that brings his work into close proximity with that of Jacques Lacan. Lacan's approach to psychoanalysis involves listening for the unsettling moments in the everyday speech of patient (analysand). Foucault's genealogy represents discourse (regularities and exclusions) as something that speaks to the subject and is only occasionally marked by moments of failure, eruption and points of inflection. In contrast, Lacan sees such discontinuities as something that punctuates the speech

of everyday life. The analytic practice, in relation to the individual patient, involves making use of these inconsistencies in order to unsettle the patient's narrative self-conception, his fantasy.

Fantasy and the Failure of the Symbolic Order

Lacan, like Foucault, accords tremendous importance to the power of the symbolic order to produce everyday "reality," as well as the speaking subject himself (Wright 1999). However, rather than simply focusing on how the symbolic order mediates our sense of reality through regularities and exclusions, Lacan draws our attention to the fact that no symbolic order is ever fully capable of becoming identical to the reality it represents. Further, he argues that our awareness of this failure is most evident in the way language is disconnected from our enjoyment/suffering/desire (Fink 1995; Stavrakakis 2003; Byrne 2003). Lacan argues that we become aware of this deficiency of the symbolic every time we fail to express our own desires or to understand what another wants. This failure reflects a foundational trauma for the subject of discourse. Further, for Lacan, this traumatic experience is universal—it is experienced by people who are in authority as well as those who are subjected to authority. Lacan argues that this failure, endemic to the symbolic order of discourse, is continually addressed through the formation of fantasies that attempt both to express the wishes of the subject and to explain/secure the subject's identity as his wishes are inevitably left unrealized or are found lacking in the moment of fulfillment.

In psychoanalytic theory fantasy exists in a register, separate from the symbolic order of discourse, that Lacan names "the imaginary." Fantasies are distinct from discourse in that they are the basis for a narrative scene composed of images as well as fragments of discourse: injunctions, idiotic phrases, stories, jokes.

The imaginary register is not something superseded by means of rational thought or human development; rather, it is a necessity for a concept of self to exist, precisely because the subject cannot ultimately say who they are or understand the desires of others. Like dreams, fantasies contain repetitive movements, idiosyncrasies and paradoxes that are arranged into a smooth narrative only after the fact to give the appearance of a stable order, a canny familiarity (Žižek 1991; Wright 1999). The differing explanations as to why the health care reform debate is a permanent, irresolvable feature of the U.S. political landscape can now be re-read through the lens of fantasy. Repetition, uncanny actors and complexity smoothed into “narrative” are the principal features of this so-called rational debate.

For psychoanalysis, fantasies are the way the subject attempts to cover over traumatic failings of the symbolic order. In the common understanding of the term, fantasies, like dreams, involve fulfillment (Wright 1999). There is, of course, an important way in which the psychoanalytic concept of fantasy departs from the common sense meaning of the term: the function of fantasy is not to fulfill a wish but to keep desire alive by explaining failure and preventing success. Health care reform is the site of many different wishes, dreams and fantasies. Just as we might express wishes in relation to our own personal health and well-being, health care reform can be seen as a series of contending wishes—the wish to live forever, the wish for caregivers to be humane, the wish for everyone to have access to care and the wish for care to be cheap are all commonly voiced desires. These wishes are both voiced and reflected in surveys, the popular press and elsewhere and it is important to understand them since their ultimate function in the health care reform discourse is to provide an explanation for the failure of health care reform.

Wish to Live Forever vs. the Wish for Humane Care

As much as mortality remains a fact of life for human beings, modern medical intervention can miraculously forestall death, giving rise to the idea that, given enough time, effort and energy, every illness or injury can be overcome. Some people articulate a wish to live forever more strongly than others who may be more accepting of death. In relation to this point, George Lundberg (2000), former editor of JAMA, repeats the following joke:

The story goes that in the United Kingdom death is imminent, in Canada death is inevitable and in California death is optional (3).

Lundberg argues that one of the principal forces behind the explosion in health care costs—and the health care crisis—is our unexamined wish to cure at any cost. The joke seems to suggest that the citizens in Canada and the United Kingdom are more accepting of mortality, perhaps too accepting, while Californians suffer from the delusion that it is possible to live forever, costs be damned. Coddington *et al.* (2000, 87) in less humorous fashion repeats the basic assertion of the joke, arguing that “increasing consumer expectations” is the most important factor contributing to runaway medical costs in the U.S.

In contrast to Lundberg and Coddington *et al.*, Berwick (2004a) argues that, while patients express a desire for the cures of modern medicine, most of their wishes (often in the form of a complaint) are for more compassionate care, straight answers from care providers and prompt delivery of services. This is not a concern unique to the U.S. health care system. A recent survey conducted by the National Health Service in the United Kingdom came up with the following “top ten” wishes from patients:

1. More and better paid staff - more doctors, more nurses, more therapists and scientists.

2. Reduced waiting times - reductions in waiting overall, for appointments and on trolleys and in casualty.
3. New ways of working - including “bringing back matron.”
4. Care centered on patients - action on cancelled operations, more convenient services.
5. Higher quality of care - especially for cancer and heart disease.
6. Better facilities - more cleanliness, better food, getting the basics right.
7. Better conditions for NHS staff - reward and recognition for the work NHS staff do.
8. Better local services - improvements in local hospitals and surgeries.
9. Ending the postcode lottery - high quality treatment assured wherever people live.
10. More prevention - better help and information on healthy living.¹³

Many of these wishes are shared by Americans as well. In contrast to “the wish to live forever,” most of these wishes seem quite modest and involve concrete changes in the United Kingdom’s National Health Service that would improve care for both patients and providers alike.

Wish for Universal Access vs. Controlling Costs

In the same way that citizens of the United Kingdom want to “end the postcode lottery” many citizens in the U.S. desire that no one should be denied access to care because of inability to pay. According to Dranove (2000) a vision of medicine as a calling motivated by something more than the “profit motive,” shared by providers and patients alike, is one of the principal reasons why the majority of hospitals continue to have a non-profit structure. While the “wish” for universal health care coverage may have been overestimated during the Clinton administration and others, it is certainly safe to say that a sense of fairness and access to at least a minimum of care are a definite part of a collective wish for health care (Samuelson 2006).

¹³ <http://www.nhs.uk/patientsvoice/topten.asp>

Currently aggregate health care costs in the United States are estimated at nearly two trillion dollars per year. As much as citizens in the U.S. want every available treatment, universal accessibility and compassionate care, they also do not want to pay for it—so the tendency is to attempt to identify someone or something to blame for the health care systems tremendous costs and present shortcomings. According to some, it is really the unwillingness of U.S. citizens to compromise on any of these wishes that leaves us in an impasse, in a condition where the politics of health care “reform” is ultimately a set of empty, impracticable gestures.

Americans want more health care for less money, and when they don't get it, they indict drug companies, insurers, trial lawyers and bureaucrats. Although these familiar scapegoats may not be blameless, the real problem is us. (Samuelson 2006)

In relation to health care there are a number of wishes that are contradictory in nature. The hyperbolic wish for immortality must be set against the more modest wishes for humane care, the noble wish for care access against the miserly wish for care to burden us with minimal social costs. It is in the contradictory nature of these wishes that we realize the full explanatory power of the psychoanalytic conception of fantasy. Fantasy as a concept allows us to understand how opposing wishes can be maintained within a single individual.

The Psychoanalytic Function of Fantasy: Castration and the Conservation of Desire

Psychoanalysis adds to the commonsense connection between fantasies, dreams and wish fulfillment by insisting that fantasies also contain a frustrating element, the “symptom”—a figure or a force that guarantees failure. Paradoxically it is in frustration and failure that the real power of fantasy is to be found. The

symptom allows the fantasizing subject to say “we could have what we want if only it weren’t for X (the frustrating element or symptom) which stands in the way.”¹⁴ While the utopian wish expressed in fantasy remains constant, the frustrating symptom changes its guises as the fantasy is restaged, keeping the subject at the proper distance from the desired object, reconciling their desire with things as they “really” are (Miller 1994; Žižek 1991). This is why, for Lacan, the ultimate function of any fantasy is castration—the subject is separated from their desire by means of the symptom (Butler, Laclau, Žižek 2000). Psychoanalysis insists that it is really the symptom which allows the fantasy to function, giving the subject a consistent identity, explaining their present unhappiness and keeping desire in play. The subject of fantasy understands themselves both through the pleasure of their wishes and the suffering caused by the symptom.

From a Lacanian perspective, the health care reform debate can be viewed as a pair of social fantasies of reform located within the same discursive terrain. On a formal level this fantasy fulfills a wish—equitable and efficient care for all—and proposes a means for its fulfillment: market rationality or government planning. At the same time, there is a symptomatic force that keeps us from getting what we want, explaining and ultimately reconciling us to a less than perfect present.

It is perhaps easiest to see the wish for what we don’t already have—national health insurance—as the site of a social fantasy. Advocates from this

¹⁴ By way of explanation Jacques-Alain Miller (1994) asks us to consider the fantasy of the racist. The hatred of the racist is directed at the other’s uncontrolled libido, smelly food, loud music, etc. If none of these particularities can really describe what makes the racist hate the other it is because they are, according to Miller, a stand in for the “lost object” that is the cause of the racist fantasy. The lost object is the enjoyment which the racist accuses the other of stealing. The racist says “I would be able to enjoy myself were it not for those people!” The psychoanalytic intervention is not to refute the racist’s claims but rather to focus in on the “lost object,” to reveal that it is only lost because it never existed in the first place.

perspective believe that redefining care as a right would “fix” the contradictions and inequities in the health care system, if only the entrenched resistance to this idea could be overcome. It is only with the addition of castration, the frustrating symptom that explains our unhappiness, that we can clearly see the health care reform debate as a clash of contending fantasies. Each pole in this debate can regard the other as its symptom. Free market reform advocates can see in the government allocation of care through Medicare something that distorts the behavior of patients and providers.

The goal of fantasy is the conservation of desire—free market reform/universal health care must remain unrealized in order to continue functioning as objects of desire. The politics of fantasy are conservative in a precise sense—alternatives and experiments are preempted. Any wish we might articulate in relation to health care reform is met by a symptom that restores inertia. So, for instance, when we express a wish for equal access to health care we are met with reminders that we cannot achieve this without giving up something else. If we want equality of access we must pay for it with longer lines. What this fantasy of “trade off” entails is a rationalization for the present condition including its inequities, shortcomings and wastefulness. Boston journalist David Brudnoy tells the story of his treatment at a Boston area hospital for cancer and his frustration with the bewildering and costly nature of health care, the routine callousness with which he was treated, and the humiliations he was submitted to. However, he insisted that it would be worse if he were in Canada.

Dictators may rail against America, but when in dire need it's our hospitals they flock to. Canadians, as proud as they are of the low cost health care for patients—the cost to the taxpayer is another matter; 22 percent of Canadian taxes go to medical care—know that

if they require access to a myriad of top-shelf machinery, they scurry here rather than wait their turn and die back home. (2004, 19)

One might be tempted to try reason in the face of this argument that the U.S. health system is the envy of the world. For instance, Katz (2002) refutes the myth of the Canadian horde fleeing state mismanaged health care. Others have pointed out that other industrial nations with national health care perform better in relation to certain diseases and public health problems than the U.S. health care system (Hussey *et al.* 2004). The problem is that Brudnoy's sentiments are not related to reason and, as a consequence, appeals to rationality would be unlikely to change his opinion. From a psychoanalytic perspective his argument is an attempt to shore up his "enjoyment"—the indignities and costs of the present system are bearable because all the alternatives are unworkable. If fantasy ultimately revolves around the preservation of desire, the maintenance of things as they are, then Brudnoy will simply come up with another explanation as to why all alternatives are impossible when confronted with the facts.

Analytic Intervention

What if the prospects for actual health care reform require us, at least initially, not to deal with the particular "realities" of the health care crisis but with the psychic structure of fantasy that keeps the health care reform debate in a state of deadlock? It is this deadlock that ultimately constitutes the subjects who participate in the health care reform debate. The Foucauldian intervention would be to lay bare the historicity of this debate, how certain subjects are permitted to speak authoritatively in relation to health care reform (policy experts), while the motivations of others are seen as partisan, pathological or simply uninformed (patients and even doctors). The Lacanian approach essentially adds to this

process a depiction of how “enjoyment” is constituted, maintained and constrained in relation to this particular fantasy.

By keeping costs under control, expanding access, and helping more Americans afford coverage, we will preserve the system of private medicine that makes America’s health care the best in the world.
(President George Bush 2004a)

One way of describing the fantasy that is at work on both sides of the health care reform debate is the belief that it is possible to “get it right.” While the quote from President Bush was uttered in defense of “private medicine” clearly advocates of universal health care are also invested in affordable, accessible quality care. Here, “getting it right” is a question of allocation that is expressed in economic terms through a discourse that brings together knowledge from economists, efficiency experts, politicians, physicians and even social activists in an effort to “fix” the problem. In both the free market and single payer iterations of this fantasy, the claim is that a particular allocation mechanism—if consistently applied—will ensure the efficient and equitable delivery of services by correcting the inefficiencies that currently plague the health care system.

The particular form that this logic takes is disciplinary. In order for us to have “efficient” markets or lean government programs we must constrain the “enjoyment” of patients and providers. Further, this “enjoyment” is expressed in relation to economic costs of health care—how much care a patient is entitled to and how much the provider can (or should) charge. It is here that our contradictory wishes for our health care to be compassionate and miraculous, efficient and universally accessible come up against, and give way to, economic “reality.” The economy here functions as a sort of paternal law that castrates the

fantasizing subject, allowing them to retain their “wish” while, at the same time, reconciling them to the “economic realities” of constrained enjoyment.¹⁵

.An analysis of the health care reform debate as two versions of a fantasy informed by a common conception will allow us to understand two things about the health care reform debate that would otherwise be missed. First, that the two alternatives “universal care” and “free market reform” tend to converge in how they understand the actual process of health care reform because they share a common understanding of the principal actors in health care—patients and providers. Second, these shared beliefs among insurers, government administrators, academics, policy experts and even the public have led to a common set of practices in terms of constraining and containing the “enjoyment” of patients and providers, reconciling the wish for care to be universally accessible, affordable, and humane with the idea that there are “real” limits. It is precisely this theoretical and practical convergence of these two “opposed” fantasies that produces the deadlock in the health care reform debate and our inability to pass to the act.

Moral Hazard and Demand Inducement

There are two concepts from mainstream economics that serve to illustrate how the fantasy of health care reform expresses both a utopian wish—for efficiency, equity, cost control—while accepting the necessity of castration. These

¹⁵ One is reminded here of Wendy Brown’s (2001) treatment of Freud’s essay, “A Child is Being Beaten.” She points out through a close reading of Freud’s text that the wish that gets expressed in the fantasy—to see other children brought under the authority of a parent/teacher—is connected to a latent desire to be the “good subject,” whom the authority approves of. This is actually a wish, in Freud’s view, to be beaten oneself. Gibson-Graham (1996) makes a similar point in relation to the economy. The global economy acts as a parental figure in many spaces making demands for firms, industries and nations to be competitive. When a union accedes to

concepts—demand inducement and moral hazard—co-evolved with the health care reform debate. Contained in these concepts is the powerful notion that both patients and providers, from an economic perspective, are egregious utility maximizers. Their rational self-interestedness, in the absence of constraint, is responsible for the ever-spiraling cost of health care. From a psychoanalytic perspective each of these theories is interested in the “enjoyment” of these subjects. The fantasy at work on both sides of the health care reform debate is to somehow reconcile the wishes of doctors and patients with the need to control costs. The twin theories of demand inducement and moral hazard offer a context in which to imagine and enact the castration of these subjects.

Demand Inducement

In 1961 economist Michael Romer made a stunning observation about a health care facility near his home in upstate New York. The hospital added 58 beds to their ward and, within a year, these beds new beds were nearly half-filled on a daily basis. At this time hospitals and doctors alike were simply reimbursed by fee-for-service insurers who had yet to develop any interest in or commitment to overseeing or regulating hospital practice. Romer reasoned quite simply that a “bed built is a bed half filled” (Dranove 2000). On the basis of this “natural experiment,” Romer was able to apply the economic concept of “demand inducement” to the health care sector. The concept of demand inducement underscores the self-interest of doctors and hospitals alike to provide patients with as much cure as possible. At the time it was theorized that treatment decisions made by physicians end up maximizing their own income as well as that of the

those demands out of competitive necessity, adopts the same interest in being “lean” or

hospitals in which they work (Mark and Redisch 1973). In the absence of any constraint, demand inducement will lead to spiraling costs and over-treatment.

Dranove argues that there are basically two sources of demand inducement or over-treatment. Ambiguity in the diagnosis and clinical treatment of an illness are “soft factors” that lead to demand inducement. They are distinct from “hard factors”—the greed of doctors operating in a fee-for-service reimbursement where the insurer has no oversight or control over his practice (Dranove 2000, 33). The difference between hard and soft factors is whether or not they are directed by intentional self-interest.¹⁶

Victor Fuchs (1974) observed that in markets with a high demand for medical services, like Florida, there was a direct relationship between supply and demand. For every 10 percent increase in the number of physicians there was a 3 percent increase in the number of operations performed. Of course, Fuchs himself admitted that it is difficult to discern whether this correlation is the result of previously unmet need being filled or if it is physicians making up for lost income

“competitive”—regardless of the sacrifices called for—is this not a wish to be beaten?

¹⁶ Demand inducement as a theory explains the motivations of the doctor as a rational actor defining his behavior as a known quantity while it admits, simultaneously, that one can never be certain if a doctor really is just interested in his personal income or if his approach to the diagnosis and treatment of illness reflects some other motivation such as a wish to be thorough, ‘on the safe side,’ etc. Experts who study technological change in relation to the provisioning of care note that there are significant differences in how we treated diseases in the 1950s, the 1970s and how we currently approach disease today. Cutler (2004) notes that the prescription for a mild heart attack was bed-rest whereas today we know that inactivity can lead to a more catastrophic heart attack. Currently many forms of cardiac interventions are more intensive. However, they require minimal hospitalization times due to reduction in the incision size and superior control in the administration of anesthetics. So while the cost of the surgical intervention might have gone up hospitalization periods have gone down. How might these shifts in the technologies of treatment affect the story we can tell about demand inducement? Was it really the imposition of outside constraint in the 1980s that brought demand inducement under control? Or was it that the nature of health care intervention and its related expenditures shifted? Given the aforementioned conceptual ambiguity of the idea of demand inducement, these additional doubts should convince us that demand inducement is not a truth but a governing assumption that produces an understanding of the “enjoyment” to be constrained.

by increasing the number of surgeries performed as his theory asserts. Given this uncertainty

Not everyone was convinced by these findings because of the ‘chicken-or-egg’ aspect to them. The data reveal that purchases of physicians’ services were higher in those markets that had more physicians. But which way did the causality run? Did physicians cause the patients to purchase more medical care (as inducement theorists claim)? Or did communities whose residents had a high demand for medical services attract a disproportionate number of physicians to locate there? (Dranove 2000, 34)

The radical ambiguity here alerts us to the fact that we can tell two completely different stories about the relationship between the demand for care and the number of physicians, their behavior, etc. In the same way, one can never be certain if a doctor really is taking a course of action because he believes that the most aggressive/expensive treatment is in the best interest of the patient or because it provides him with the highest level of reimbursement. Nevertheless, since the late 1960s a consensus has emerged in which both public and private insurers act as if demand inducement were real. Shortly after their creation, Medicare and Medicaid programs internalized the results of Romer’s “natural experiment” and began setting limits or “caps” on reimbursement for medical procedures in an effort to limit the effects of demand inducement. Some maintain that this intervention caused physicians and hospitals to charge a higher rate for the same procedures for patients with private insurance. The eventual result was that many private insurers adopted capitation as well—shifting from fee-for-service reimbursement to a system of pre-specified payments (Dranove 2000, 26).¹⁷

¹⁷ MCOs, including Kaiser, had been applying the principal of capitation-based reimbursement since their inception. In the early 70s, though, MCOs were relatively minor players in the insurance market.

Moral Hazard

Moral hazard is the complement to demand inducement. While the latter is focused on the desires of the physician the former is concerned with those of the patient. The basic theory of moral hazard comes from a generalized conclusion about the socialization of risk. The less “accountable” an individual is for the circumstances that befall him, the more willing he is to take risks (Dranove 2000). In the early 1970s the RAND group conducted a massive study involving 6000 patients in order to quantify the moral hazard and to determine a sufficient negative incentive to discourage over-use of medical care without negatively impacting the patient’s health. This study imposed a patient co-payment which required patients to pay somewhere between 25 and 95 percent of medical costs while another group received care for free. The study found that people with free care used health care services 30 percent more than those who made even the smallest copayment.

The RAND study was commissioned in connection with the Kennedy-Mills bill of 1974. While the bill did not come to be law of the land, the RAND study had a profound effect upon the private insurance industry.

After the RAND results were published, insurers realized that copayments could eliminate excessive moral hazard utilization without eroding quality. They offered more plans with higher copayments and slightly lower premiums. Consumers (or at least their employers) eagerly accepted the new plans, and today a typical indemnity insurance plans requires enrollees to pay for 20 percent of medical costs and or pay deductibles of \$250 to \$500 before coverage begins. (Dranove 2000, 31)

Insurers, to varying degrees, took to heart the concepts of demand inducement and moral hazard and attempt to create a system of oversight that would restrain patient demand and control provider costs. Many of the early MCOs, such as

Kaiser, had already adopted these practices years ago, making them more attractive to employers.

Just as demand inducement asks us to act as if we know that physicians are self-interested actors even while admitting that that they aren't always/might not be, the theory of moral hazard asks us to accept a certain view of patients' desire for care. The idea here is that patients, in the absence of constraints or personal accountability, will demand as much care as possible from providers. While it is true that there are some individuals, motivated by hypochondria or a desire for attention, who ask for as many medical tests and procedures as possible, moral hazard asks us to suppose these individuals are the rule rather than exception. Given that there are public health campaigns that practically beg people to get particular inoculations and preventative screenings—from flu shots to colonoscopies—it becomes difficult to sustain this idea of an infinitely demanding patient that is the complement to the greedy doctor. More recently, state level efforts that have attempted to impose copayments upon indigent Medicaid recipients have been criticized for creating barriers to access. Critics argue that Utah's recent experiments with elevated copayments will make indigent patients less likely to seek necessary care, running the risk of turning manageable health problems into very expensive ones (Johnson and Ableson 2005). Thus, the same irresolvable ambiguous/split understanding of doctors in demand inducement theory is replicated in the theory of moral hazard.

The social fantasy embodied in the figure of the needy patient and greedy provider changes and evolves over time, but the central function of these ideas is to legitimate the constraint and regulation of enjoyment. The ambiguity of physician and patient motivation and desires is disavowed in favor of an economy

of discipline that tells us we must constrain their enjoyment. The fact that this discourse never fully articulates the desires of patients and physicians—that ambiguity remains, no matter how much it is disavowed—has consequences for health care reform discourse.¹⁸

Demand Inducement, Moral Hazard and the Real

In the context of the health care reform debate, “allocation” is the site of a contradiction. On the one hand, there is a genuine wish to give everyone access to health care. Indeed, I would argue that this is one of the reasons why there have been continuous efforts to legislate access to care as a right. Nominally, even those who are committed to a market-based approach to health care reform believe that unconstrained competition in the health care field will drive down costs and make care more accessible and affordable. On the other hand, there is the familiar belief that it is truly not possible to provide for the needs of all without consequences—the belief that equity would come at the expense of quality. As Cutler puts it:

It’s great that more people will be covered because of health care reform, but who will volunteer to sacrifice their own care to achieve this? Health care reform becomes synonymous with rationing. (Cutler 2004, 122)

Thus, the fantasy of universal health care allocation is associated with the fear that, while people’s demand for care is potentially infinite, time, money and society’s productive capacity are not. Both sides of the debate presume that scarcity is a definite and inescapable facet of health care and indeed of life itself.¹⁹ In

¹⁸ Lacan (1968) is quite salient here since he argued that the ambivalent subject is the inevitable unconscious product of bureaucratic discourses like this one. The attempts to understand and administer the desires of patients and physicians fail of necessity because no singular representation can fully capture what it is that they want.

¹⁹ Dranove (2003) provides us with an excellent example of how scarcity is the presumed ontological ground that governs society. To explain the ubiquity, efficiency and superiority of market-based rationing Dranove uses the example of pizza being sold in the marketplace. He

psychoanalytic parlance scarcity constitutes the Real—yet another register, separate from the symbolic/discursive and the imaginary register of wishes, fantasy and castration.

One cannot discuss the allocation (rationing) of a resource like health care without imagining that the quantity of care to be allocated is fixed, that the resource itself is scarce. The condition that fixes our social capacity to produce health care is the burden that it places on the rest of the economy. For instance Kriss (2004) argues that the state of Massachusetts is faced with a choice of either constraining Medicaid spending—effectively rationing the care that it allocates to the poor—or raising taxes to keep pace with the demand for care. The danger, we are told, is that this runs the risk of driving the tax base from Massachusetts while marginalizing competing social needs for safer streets, bridge reconstruction, etc.

The Lacanian concept of the Real bears some resemblance to Foucault's notion of the extradiscursive. While the latter concept is meant to describe what falls outside of the regularities and exclusion of a particular discourse, the Real is a

points out that we readily accept market-based rationing of pizzas and that it would be absurd to create a government bureaucracy to make sure that everyone is getting their fair share. According to economists, goods are rationed if, under the condition that goods are free, demand exceeds supply. By this definition, virtually all goods and services are rationed. After all, few individuals have as much "stuff" as they would if everything were free (Dranove 2003, 2). By means of this example Dranove begins to establish the case for the allocation of medical goods and services on the basis of their cost effectiveness. He argues that markets take scarcity into account, expressing the difference between demand and availability through price. What is clear from his original example is that there is a connection between the finite quality of goods, their ultimate scarcity with respect to demand, the necessity of allocation or rationing, and the superiority of free market mechanisms. It is at this point that we must insist that there can be non-market allocations of goods that are not compelled by scarcity. Indeed, we don't need a government bureaucracy to tell us how to allocate pizza, to continue with his absurd example. Most of us allow a sense of fairness among family and friends to govern the allocation of pizza after we have purchased it. The sale of pizza may be rationed in the market but its allocation among friends may proceed along the lines of a completely different ethic than ability to pay. At a typical college party this same ethic of fairness gives way to yet another logic—to each according to his need. The consumption of food and drink on the basis of need is not only ethical; it is the source of enjoyment.

“hard kernel” that is internal to the symbolic order. Fantasies and their symptoms constantly shift, the discourse of health care reform as it is practiced by economists and policy experts can change focus on how to contain costs, optimize, etc., but the Real of scarcity functions as a “quilting point” that sutures the symbolic and imaginary layers together. Undoing this suture would unravel the terms of the discourse. Both sides of the debate are faced with the task of keeping the Real of scarcity at bay. The decision between these two alternatives seems to revolve around equal accessibility and explicit rationing in the universal care approach and free market choice and the exclusion of some populations. Thus it is really no surprise that the actual process of health care reform in the 1990s revolved around a compromise between these two unpalatable alternatives. To wit, the practical recognition of demand inducement and moral hazard has led to a convergence in regulatory technique—the establishment of a compromise position occupied during the 1990s where MCOs were offered as the solution to the health care crisis.

MCOs and the Domestication of Scarcity

The concepts of moral hazard and demand inducement operate within a larger symbolic economy of competitive constraint. While these ideas were developed in relation to both public and private allocation schemes it was the MCOs that really came to embody their logic. MCOs went from being a “west coast fringe” type of insurance to becoming the dominant form of insurance in the period from the mid 1980s to the mid-1990s (Anders 1996; Herzlinger 1997; Dranove 2000; Cutler 2004). Nixon apparently foresaw this when he put forward his scheme for an employer mandate to provide care—suggesting the MCOs might possess the appropriate solution, while Clinton actively embraced MCOs as the

vehicle for managed competition. The consensus was that MCOs were capable of confronting run-away costs and scarcity with their particular approach to optimization. By the end of the 1990s the reputation of MCOs was severely tarnished. Not only are they seen as having failed to contain costs, they are frequently regarded as heartless purveyors of inferior care—asking doctors to accept less pay while giving them more work, having patients pay higher premiums and telling them to expect less care. In the end they became associated with the very “scarcity” they were designed to keep at bay.

During the 1980s MCOs tended to sell themselves to business executives by insisting that they could control costs through intensive managerial oversight. In place of the “hands off attitude” of traditional fee-for-service insurers MCOs are actively involved in overseeing care providers, ensuring that the care they provide is adequate, efficient and cost effective. They have tapped into the language of Total Quality Management—a set of concepts relating to manufacturing efficiency—that had become a focus of attention in business schools and other academic settings in the 1980s (Anders 1996). MCOs deploy very similar strategies for cost containment in their relationships with physicians, hospitals, pharmaceutical companies and other providers in the field. The story of these various approaches to cost containment can be told in relation to both the techniques that MCOs developed and the contradictions and failures that ensued from their application.

MCOs, Doctors and Hospitals

According to Dranove (2000), MCOs have come up with four different ways of securing the services of doctors and other health care providers. The most direct “staff model” approach essentially transforms doctors from independent

operators into wage employees, eliminating demand inducement. There is no financial gain for over-treatment. While Kaiser has been successful, historically, with its group model the dominant organizational form is that Independent Physician Association (IPA) or networked approach

IPAs and the network model HMOs have built on the existing provider infrastructure. They are often little more than a nexus of contracts between insurers and providers, without much brick and mortar to show for them. Many IPAs were formed by groups of physicians who wanted to retain their current style and their independence. (Dranove 2000, 69)

In spite of the apparent degree of informality this model still has the MCO negotiating reimbursement rates with doctors, effectively allowing them to use their bulk purchasing power to obtain a rate of discount in exchange for a “guaranteed patient base.” The basic idea in either approach is that MCO organizations put themselves in a position to dictate the physician’s fee by controlling access to the market.

MCOs treat hospitals in much the same way that they treat physicians. In any given market they contract with only certain hospitals offering to direct patients their way in exchange for rate decreases (Anders 1996; Herzlinger 1997; Dranove 2000; Kleinke 2001; Cutler 2004). This relationship can have a significant impact on the organizational form of the hospital and even the range of services that they provide. Anders (1996, 96) tells the story of Good Samaritan Hospital in Los Angeles. Reduced reimbursement rates prompted Good Samaritan to transform Coronary Artery Bi-pass Grafts (CABG) into an assembly line process. These innovations allowed Good Samaritan to go from a facility performing two hundred and fifty CABG in 1985 to thirteen hundred by 1990. Even though reimbursement rates had fallen nearly five-fold, this strategy nearly doubled hospital revenues.

According to Anders this strategy worked well for Good Samaritan until competition from other hospitals allowed MCOs to further decrease reimbursement rates.

MCO advocates tell this type of story in order to show how this incentive transformed the way medicine was practiced. Selective contracting and capitation essentially forced Good Samaritan to achieve an economy of scale. Theorists like Dranove (2000), Herzlinger (1996) and others would argue that there is an additional benefit—surgery volume reduces error through specialization. Hospitals become very good at particular techniques when their associated physicians perform the same operation over and over again. It is equally possible to tell a different story, however. Good Samaritan, by some measures, had a post-surgery mortality rate of 10 percent by the mid 1990s, more than five times the mortality rate of a neighboring Kaiser facility (Anders 1996, 99). While Good Samaritan officials said their mortality statistics were a reflection of the difficult cases they took they also maintained that some level of mortality needed to be accepted as the cost of running an efficient operation.²⁰

MCO and Pharmaceuticals

In the same way that MCOs tend to use their size to influence the pricing and even the nature of the services provided by hospitals, many have attempted to exert pressure over pharmaceutical companies. Many MCOs maintain formularies—lists of drugs that they allow their doctors to prescribe. In order to get on these formulary lists pharmaceutical companies will offer their products to

²⁰ Coddington *et al.* (2000, 98) argue that MCOs were able to engage in selective contracting with hospitals and doctors because Medicare payments exceeded those allowed by MCOs. In other words, in the same way that Medicare's early adoption of capitation shifted costs

HMO affiliates at deeply discounted rates. The formal justification for formularies extends beyond discount pricing however. Some MCOs hire pharmacy benefits managers (PBMs) in order to negotiate deals with pharmaceutical companies while others outsource the work of evaluating the efficacy of particular drugs and procedures to firms that specialize in utilization review (UR). This relationship changed following the deregulation of pharmaceutical advertising in 1996, during the second term of the Clinton administration. At that time, many MCOs came under pressure—through their doctors directly and their patients indirectly—to allow particular, newer/non-generic drugs into the formularies that had been excluded in favor of older, cheaper drugs (Anders 1996, 49). In some ways this tipped the scales back in favor of the pharmaceutical companies. Further, as their importance became obvious many PBM or UR companies began to charge higher rates to MCOs. In other cases they were acquired by pharmaceutical companies, negating their “independence,” and undermining their ability to arbitrate between insurers and pharmaceuticals (Anders 1996, 50).

If the relationship between MCOs, physicians and hospitals is marked by a central ambivalence—cost control vs. possibly changing the very nature of care—the relationship between MCOs and the pharmaceutical industry tells us a different story. What was at stake in this struggle was the share of profits that would accrue to each party. The pharmaceutical companies were regarded as having gained the upper hand in this struggle by the end of the 1990s. As a result, health care costs began to rise, increasingly reflected in elevated health care premiums passed along to businesses and their employees. This development, however, cannot be

to indemnity insurers in the 1970s, MCOs shifted costs back to government programs in the 1990s,

separated from the changing relationship between MCOs and their enrolled patients.

MCOs and Patients

MCOs have, historically, been tremendous advocates of preventative health care (Anders 1996, 86). Routine care—mammograms, cholesterol screening—are the stock and trade of managed care because these early interventions prevent people from getting sick in the first place. Preventative medicine, by definition, keeps people who are well from getting sick. There is, of course, nothing wrong with the idea of preventative medicine. However, as one cardiologist points out

We're creating a massive industry devoted only to customer service, wellness, and prevention,' he says. 'The tragedy is that some people are quite ill and don't get referred to specialists.' (Anders 1996, 227)

Following the prescription that an ounce of prevention is worth a pound of cure can, on occasion, have disastrous consequences when angina is misdiagnosed as heart burn and cost considerations completely override the precautionary attitude of medicine.

The ability of MCOs to contain physician, hospital and pharmaceutical costs depends upon their ability to constrain patient choice—for instance, by requiring patients to be pre-authorized for certain treatments and through disallowing particularly expensive treatments whose efficacy has not be substantiated. Their ability to bargain over the price of these various care costs rests in the way that they control or speak for patient demand. These cost containment strategies made them attractive to employers in the 1990s and placed them at the center of Clinton's plan for "managed competition" (Shelton 2000; Kirsch 2003; Cutler 2004).

while appearing to effectively "manage costs."

Clinton's plan called for an expansion of programs that extended coverage to those currently outside of both employer-based plans and federally directed programs. While this plan was ultimately thwarted, many states adopted this same approach to reforming Medicaid, replacing government administered care funds with plans privately managed by HMOs. Tennessee's effort was treated as a model approach in which contracts were offered to firms that promised to keep cost increases below 8.6 percent per annum. This effort was criticized for the tight-fisted approach to patient benefits and the seemingly irrational restrictions placed on patient choice (Anders 1996). It was ultimately this dissatisfaction that led to the collapse of the fantasy that MCOs could "fix" the health care problem.

MCO Meltdown and the Reemergence of the Real

The use of selective contracting, utilization review and formularies are all attempts to cope with demand inducement and moral hazard. However sensible MCOs appear, they have become almost universally reviled since the late 1990s.

United Health Care, one of the largest HMOs in the country, decided in 1999 to end preauthorization requirements for most major procedures. The outrage caused by the requirement was just too great. Managed care is easing up in area after area, in response to consumer and physician complaints (not surprisingly, the easing up has been accompanied by an increase in medical care costs...). The strict managed care era is already on its way out. (Cutler 2000, 98-99)

People resented MCOs precisely because they did what they were designed to do—constrain access (enjoyment) in order to control costs. Regardless of their particular assessment of MCOs, Kleinke (2000), Dranove (2000) and Cutler (2004) believe that "patient bill of rights," passed in many states, fundamentally undermined their ability to contain costs by limiting the ability of MCOs to engage in selective contracting. Even champions of managed care like Dranove (2000) admit that

If MCOs do not evolve beyond discounting, perhaps patients might be better off under a single payer system in which the government achieves lower costs by dictating price reductions. At least in such a system there would be no marketing expenses, no medical underwriting, and full, portable insurance. (171)

The irony here is that MCOs were supposed to avoid the pitfalls of explicit rationing by presenting patients (and employers) with a variety of choices framed in the context of competitive pressure.

It is here that a curious parallel develops between the role that MCOs play in the social fantasy of health care reform and the clinical setting of psychoanalysis. Žižek (1991) points out that most analysands initially come to the analyst hoping to restore the efficacy of their fantasy and its symptoms. MCOs, as we have known them, have failed to contain costs (domesticate scarcity). The future of reform discourse revolves around the task of either restoring managed care's efficacy within the fantasy frame or a search for an alternative.

Health Care Reform, the future of Fantasy

Herzlinger (1996), Colie (2003), Dranove (2000; 2003), Coddington *et al.* (2000), Cutler (2004), and Berwick (2004) all offer prognostications and prescriptions for the future of health care reform in the post-managed care era. If the principle objection to the MCO intervention was that it limited patient choice through selective contracting—violating the patient/physician bond—these new ideas attempt to address this by increasing the patient's ability to choose. These new reform ideas are associated with concepts like “patient empowerment” and “consumer driven health care.” This same language has found its way into the recently passed Medicare Reform Act of 2003, which stresses the link between informed consumers, the exercise of personal freedom and “new” approaches to cost control.

Each of these authors stresses how the “empowered” health care consumer will be better able to make effective choices about their own health care and that, further, the exercise of choice will enable innovation, improve services, drive down costs and increase access. While the basic tenet of this fantasy remains “getting it right” there are several contending theories on how to do this. What all of these strategies have in common is that they attempt to disavow scarcity in favor of creating more “choice” for consumers (patients and employers). Rather than installing the MCO as the paternal figure that administers/controls the patient’s access to care, these strategies imagine that the consumers will discipline themselves if they are “empowered” to do so.²¹ In spite of this difference one can see in these various proposals the precise way in which the Real of scarcity will return.

Educating the Consumer: HEDIS and its Audience

Dranove (2000) imagines MCOs reorganizing themselves to place greater emphasis on educating the final consumer—the patient—so that they can make informed choices based on the quality of the actual services they are purchasing. In order to evolve beyond “discount medicine,” which appeals to those who pay for health care (tax payers, employers); MCOs must devise ways to get the patient to trust the quality of services that are being provided to them. Dranove observes that in an earlier era people made decisions about medical care on the basis of liking or trusting their primary care provider. He argues that that may have been fine at a time when physicians were providing little more than compassion but, in

²¹ Once again a parallel between a Foucauldian and psychoanalytic analysis presents itself. This shift from an MCO driven approach to cost containment to one of consumer self-discipline could be seen as the move from direct parental authority to one where the subject has internalized

the era of modern medicine, we should be able to come up with criteria other than someone's bedside manner. He argues that MCOs present us with an opportunity to track patient outcomes on a large scale that might lead to a different way to evaluate care quality.

The rise of managed care, combined with the ongoing revolution in the health information technologies, offer patients an unprecedented opportunity to solve these problems. Selective contracting enables MCOs to get better prices from providers. Outcome based research enables MCOs and providers to identify the most cost-effective ways to treat and manage disease. Report cards help patients identify some of the best and the worst MCOs and providers. These new solutions to the shopping problem are moving the health economy towards an ideal combination of low prices, efficient production, and high quality—in other words, value maximization. (Dranove 2000, 175)

Dranove argues that MCOs had already come up with this idea by the mid 1990s. The National Committee for Quality Assurance—an MCO industry organization—began to produce a score card that evaluated the quality of services provided by MCOs. The Health Plan Employer Data and Information Set (HEDIS) allowed one to see the trade-off between selective contracting and quality in order to see whether one was getting quality medicine or simply a break in terms of price (Dranove 2000, 156-9). The problem with HEDIS, according to Dranove, is that its reports were ignored by the target audience—employers. Dranove reasons that if this information could be put in a format that was accessible to the actual consumer—the patient—it might not be ignored but instead used to strike a balance between quality and cost control. Thus, Dranove's proposal is to “empower” the consumer through education. Consumers could discriminate

the “name of the father.” Foucault used the concepts of “bio-power” and “governmentality” to describe this same type of shift in the nature of disciplinary power.

among providers (or among MCOs and their affiliates) and that would create competitive pressure to contain costs and improve care quality.

Health Savings Accounts and Consumer Driven Health Care

While Dranove would seek to salvage MCOs, others propose to do away with these “dinosaurs” altogether. Herzlinger (1997) was an early advocate of the idea that an “empowered” consumer is one that is personally liable for their health care costs and, for that reason, is invested in being savvy. She pointed out that there is price competition in certain sectors of the health care market where insurance is largely uninvolved—eye care, for example. Many policy experts dismiss Herzlinger’s extreme vision of market-based health care reform. Many of the commercial ventures Herzlinger and other championed, where consumers pay out of pocket—walk-in medical centers, bio-scanning facilities—have proven to be market failures (Kolata 2005; Marmor 1998). While consumer-direct approaches to the health care market have not been cross sector successes, Herzlinger’s idea of “empowered/responsible” consumers continues to find powerful advocates.

I'm a strong believer in what they call health savings accounts. These are accounts that allow somebody to buy a low-premium, high-deductible catastrophic plan and couple it with tax-free savings. Businesses can contribute; employees can contribute on a contractual basis. But this is a way to make sure people are actually involved with the decision-making process on health care. (George Bush 2004c)

President Bush feels that tax deductible health savings accounts will create a greater sense of personal responsibility for health care spending decisions with individual patients. It is important to note that HSAs are not imagined as a complete replacement for health insurance. Rather, they would constitute a financial cushion that would allow people to purchase less expensive insurance plans—“low premium, high deductible catastrophic plans.” These plans would be

un-expensive for individuals and employers unless they were put to use. In the even of catastrophic injury or illness HSAs would serve as the financial equivalent to an air bag.

Gabel *et al.* (2002) point out that there are two terms that are widely associated with consumer empowerment— “defined contributions” and “consumer driven health care.” These concepts have two different meanings but are frequently used interchangeably. Consumer driven health care refers to greater personal choice in defining health care benefits and deciding the level of personal risk that one is comfortable with (the trade-off between premiums and deductibles). HSAs would be the logical culmination of this concept. In contrast “defined contributions” refer to health care plans that cap the employer’s contribution on health insurance spending. Obviously, low premium high deductible catastrophic plans are attractive to employers seeking to define their contributions—this is precisely what HSAs legitimate.

What might it mean that these two terms are frequently conflated? It is fairly easy to see that the two terms seem to speak to two different concerns—the “defined contributions” reflects a commitment to cost containment (for employers) while “consumer driven health care” is concerned with offering consumers more choice. If we read these two terms together “empowering the consumer” means allowing them to decide how much they value risk versus coverage. From a psychoanalytic perspective the use of these two terms as if they had the same meaning is symptomatic. It expresses a new fantasy of health care reform where the old central question —national health insurance vs. free market reform—is displaced by another concern; promoting consumer choice to determine their own

level of risk.²² The violence of this discursive move is that it is essentially a forced choice in which people's present age, employment, economic circumstances and health situation will determine what they are "free" to choose.

Market Segmentation and the Return of the Real

The trend towards more "consumer-driven" health insurance sounds wonderful. We like to have choices. One size does not fit all. Choice promotes competition between health plans and therefore improvements in quality and efficiency and better choices. Choice and competition are all American marketplace values. So, surely, consumer-driven health care must be good. It is particularly popular with many Republican legislators, who want to promote this model for both employer sponsored insurance and Medicare. (Taylor 2003, 195)

The current discourse of health care reform is an attempt to redefine health care access as a personal trade-off decision between risk and insurance. The hope is that this will create competitive pressures, both in the insurance industry and in the health care sector as a whole, which will gradually drive down the costs of health care through the exercise of consumer preference.

While the notion of free choice has a powerful ideological appeal, it cannot allay all anxieties. The Institute for the Future (2000) raised concerns about consumer empowerment in their projection of current trends in the health care industry through 2010. One of the likely scenarios they predict is the "emergence"

²² These concepts find their public sector complement in the clause of the recently enacted Medicare Reform law that mandates that a committee be formed to implement a pilot study where Medicare would be replaced by the granting of individual Medical Savings Accounts. This idea, which is espoused in a variety of forms, would replace a single government funded program with a uniform governance structure with a "market place" in which individuals would be able to choose between a variety of coverage levels.

Cutler (2004) advocates for a particularly progressive version of MSAs that would be modeled after the way federal employees obtain insurance. Funds would come from a progressive tax abatement that would range from several thousand dollars for those with the lowest income to nothing for those with income above a certain level. The biggest problem Cutler sees with this proposal is essentially a free rider problem—some people would simply take the tax abatement and consume other things (cars, stereos, etc.). To avoid this Cutler proposes that the purchase of insurance be mandated by law. In other words, in the same way that many states mandate that

of a three tiered medical market—a minority enrolled in traditional high premium indemnity insurance, a large portion of the population enrolled MCOs, and another large segment dependent on government programs. Coddington *et al.* (2000) points out that only the top two tiers will really be in a position to steer the development of the health sector in a consumer driven system. The hope is that the top two segments will constitute a driving force that will lead to a reform of the entire health care sector through price/quality based competition. What is left unanswered in this fantasy is whether this sort of segmentation will simply create (or reinforce) the belief that people who are in the top two tiers should receive better care than those in the bottom.

There is another likely consequence of segmentation of the insurance market—that insurance providers will continue to attach different costs to different levels of coverage. The further diversification of insurance products will likely lead to a situation where healthy individuals will purchase policies on the basis of price while sicker (or older) individuals will be corralled into higher priced plans. There is of course a certain sense in which this is just—younger people tend to be healthier but also have lower incomes while older people tend to be sicker and tend to have higher incomes. On the other hand, one is left to wonder how plans that target those most likely to be ill will remain profitable if the healthy population chooses only low premium high deductible plans. It is this problem of “adverse selection” which forces Cutler (2004) to conclude that some form of governmental oversight would need to be in place in order to assure that the sickest individuals are not simply priced out of the market even though it is

collision insurance be purchased by automobile owners the federal government would require

illegal to deny coverage on the basis of pre-existing conditions. Others predict a grimmer scenario in which the discourse of choice will fundamentally undermine insurance as a concept. Insurance is a form of solidarity that is predicated on uncertainty.

The fundamental problem with the current trend toward consumer choice of health plans is that we know our health status and can make a reasonably good estimate of how likely we are to need much health care in the next year. We don't know if our house will burn down . . . so we willingly buy insurance to protect ourselves against something that we know may happen but is unlikely. For these types of insurance we recognize and accept that the fortunate majority pays to subsidize the unfortunate minority. But insurance doesn't work if informed buyers can predict the future. (Taylor 2003)

This has led some to conclude that the pursuit of “consumer choice” and “defined contribution” insurance reform will lead to a collapse of the health care system as we know it (Taylor 2002). What's odd, of course, is that the “likely scenario” is not a projected future trend but an already existing reality. The crisis that Taylor and the Institute for the Future predict is already upon us. Consumer choice is a failed attempt at disavowing the reality of scarcity/exclusion that is already present for people who have little access to care.

Contemporary State of the Universal Alternative

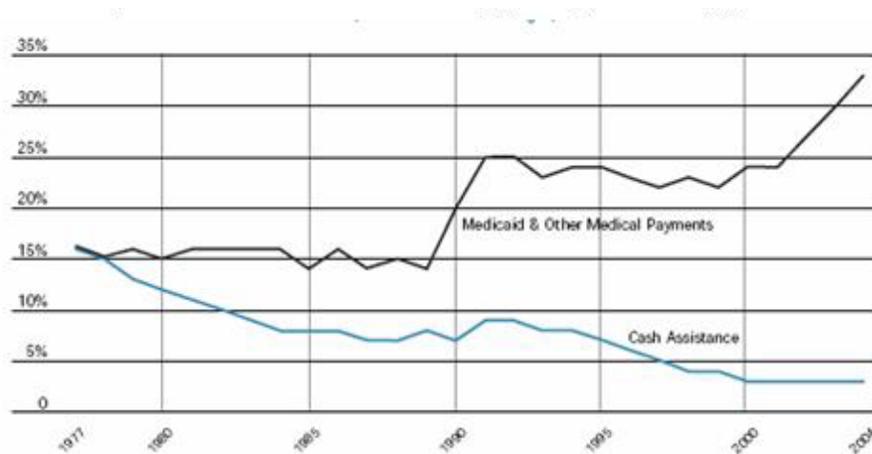
A wonderful senior citizen activist, an old friend, died recently. When she got to the Pearly Gates, St. Peter told her: “You've worked hard all your life to make health care affordable to everyone. For your all your good work you get to ask the Lord one question.” My friend stood up tall in front of the Lord and said, “I remember when FDR was about to propose national health care at the same time as Social Security, but the doctors were opposed and he was told that he might lose both if he pushed too hard, so he let it go. And I can still see Harry Truman, at the back of his train on a whistle-stop, promising to fight for national health insurance and that was a big reason he surprised Mr. Dewey like he did. But the doctors had their way with him in Congress too. Even Mr. Nixon had a plan but it was

insurance be purchased by all individuals.

different from Teddy Kennedy's and never went anywhere. So my question is, will we ever see a time when everyone in our great country has health care?" The Lord paused a moment, and said, "Yes my daughter, we will... but not in my life time." (Kirsch 2003)

This joke, told by long time health care activist Richard Kirsch, has been repeated by many others (e.g., Berwick 2004). What this joke appears to reflect is the idea that it continues to be impossible to "pass to the act" of reconfiguring health care as a basic right even though it seems to be both a logical proposition and a felt desire of many people in the United States (Butler, Laclau and Žižek 2000).

Instead of passing to the act of establishing care as a right and dealing with whatever social contradictions emerge as result of this commitment, we have a politics of exception where the right to care is provisionally extended to people who find themselves on the fringe of an employer-based health care system. Providing coverage to these populations on the socio-economic fringe is seen as having a social cost, especially at the level of the state governments that are charged with the task of administering federally directed Medicaid funds. The end result is that care access for the poor, which takes up an ever larger portion of the state's discretionary spending, is seen to come at the expense of other forms of social spending. Kriss (2003) uses figure 2.2 (below) to describe the dilemma in relation to Medicaid spending in Massachusetts.



Source: US Bureau of the Census and Mass. Executive Office for Administration and Finance

Figure 2.2 Medicaid and Public Assistance (as percentage of state budget)

Of course, the simple answer to this dilemma that pits Medicaid against other forms of relief and discretionary spending (on schools and roads for example) would be to “enlarge the pie” by raising taxes. This obvious solution is met with fierce protest that increasing the tax rate in Massachusetts will only drive businesses and individuals out, leaving the state with lower tax revenues and, in all probability, even greater numbers of uninsured people.

Vladeck (2003), in reflecting on the state of the debate of health care reform comments on the gradual displacement of calls for health care as a universal right with a procedure where people advocate for a piecemeal expansion of care to exceptional populations. Universal health care advocates are left in a position of arguing that the right to care will be established in a piecemeal fashion.

Somehow, over time, this particularistic strategy has been transformed into a normative imperative about how to do politics in the United States. According to this view, the only possible change is incremental: expansions in public health insurance have not been sufficient to reduce the number of uninsured. The private health insurance system has been unraveling at a pace roughly equal to the expansions in public programs. (Vladeck 2003, 1 of 2)

One effect of this shift in the debate is that state officials can become heavily invested in both defining these “exceptional populations” who qualify for state benefits and in ensuring that Medicaid and free care dollars are stretched as far as they can possibly go. Advocates are left arguing for the preservation of entitlements for one population or another, creating a situation in which the mental health needs of children might be pitted against the purchase of protease inhibitors for indigent AIDS patients.

Thus, there is a curious imbalance in the contemporary incarnation of the health care reform debate. While the state constrains spending through an explicit rationing of care advocates of a free market alternative use a language of “choice,” embodied in an expanding range of insurance products, in which the consumer is “free” to determine their own level of risk, coverage etc. Advocates of universal health care can make a number of compelling arguments in support of their position. Given the ever increasing role that the state plays in the allocation of care, Woolhandler and Himmelstein (2002) argue that the U.S. already almost has universal care. Reinhardt (2000) points out that Medicare and Medicaid have considerably lower non-productive costs, such as administrative overhead, compared to private insurance firms. Satcher and Fryers’ (2005) argue in favor of renewed commitment to public health spending precisely because such an investment improves well-being and will lower costs. While all of these arguments are compelling, at the level of social fantasy, we are faced with an opposition between “rationing” vs. “free choice.” Perhaps this is the reason that even advocates of care as a “right” regard their position as something of a joke. In the context of the current debate, “right” is associated with a rationing, sacrifice or restriction of individual liberty. As long as the debate remains framed in this way

the free market position is likely to be ideologically-dominant even as the state's role in allocating care to exceptional populations continues to expand.

It is at this point that I would like to take the risk of imagining that the task before us is the same one that confronts the analyst. The analytic technique is to interrupt the repetitive iterations of the fantasy by breaking the narrative flow of the patient. This can take the form of a simple utterance, "I see," at moments during the analysis or questions that shift the viewpoint of the patient, disrupting the explanatory power of the fantasy and its symptom by offering an alternative explanation. For both free market and single payer health care reform discourses, scarcity is the symptom that the fantasies continuously attempt to address or ameliorate. We, in the role of the analyst, are in the position to ask the following provocative, seemingly naïve question. Why isn't the solution to the shortcomings of the present system simply to expand the capacity of our society to produce care? If there is growing need—aging baby-boomers, more obese and chronically ill people, etc.—why isn't the simple solution the right one?

CHAPTER III

THE ECONOMY OF DIFFERENCE AND COMMUNITY IN HEALTH CARE: THEORY AND METHODS

Introduction

Health care reform discourse, in its attempts to understand, address, or contain the “desires” of patients and providers, represents them as split/ambivalent subjects.²³ The patient is at once a rational subject capable of making responsible decisions in relation to the purchase of care and insurance and an all-demanding subject whose irrational demands threaten to overwhelm society. Providers, especially doctors, are at once seen as dedicated professionals and unscrupulous subjects whose social status gives free reign to their greed. Is it any surprise then, given the representation of its principal actors, that access health care, while treated as a “right,” is a right whose exercise must be vigilantly constrained? The choice we are presented with is to accept either the social exclusions of the current mixed system or a universal alternative where constraints will be imposed on all. What we are confronted with is not a rational debate between contending positions but contending social fantasies that remain, “regrettably,” unrealized. In contrast, the actual process of reform—optimizing the care delivery process, imposing “rationing” upon those enrolled in government-directed healthcare—can be seen as so many efforts at domesticating the anxiety that a presumed scarcity of

²³ This contradictory representation of patients and providers pervades health care reform discourse. To remind us again of a key insight of psychoanalysis it is precisely this because of this inconsistent/split representation that we can say the “subject” is the unconscious product of this bureaucratic health care reform discourse. In other words it *goes without saying that doctors and patients are like this*. Like other elements of the unconscious that cannot be finally or completely enunciated/signified, “patients” and “providers” are intrinsically ambivalent or split in nature. In light of this, it is unsurprising that the same theorists, Dranove for instance, can have such a contradictory imagination of providers and patients.

care engenders. As we saw in the conclusion of chapter II, scarcity is the product of an economic discourse which locks the process of reform in a circular drive to constrain/optimize health care spending. Health care spending can never be too constrained; patients can never become rational enough while providers are forever streamlining their intake process. How can this asymptotic situation, where the goal is never reached, create anything other than a climate of contention and dissatisfaction?

Lacan would propose that a miserly discourse, like health care reform discourse, with its steady application of reason to the problem of scarcity constantly runs the risk of generating its own opposite—a hysterical discourse of protest in which all efforts are insufficient, all knowledge inadequate. Health care reform discourse can be hystericized because the desires of patients and providers can never be fixed or finally pronounced. The aim of health care reform discourse is the production of social harmony that continually provokes a hysterical response—“this does not satisfy my interests!” The subjects of reform discourse are trapped between drive to “get it right” and the hysterical insistence that “getting it right is impossible.”²⁴ In chapter II we saw how the mixed system of care allocation in the United States foments endless recriminations with each side blaming the other for the failure to reach the goal. Since government and private insurers and public and private hospitals tend to engage in the same practices to control costs and optimize care delivery, the hysterical position is, in accordance

²⁴ The scarcity of resources is intrinsic to our conception of the economy of care—it is an ineradicable horizon of anxiety for reformers, patients, and even providers. From this perspective every new drug or diagnostic technique incites demand and provokes anxiety even as it eases ailment. While the social division of labor and the ever-expanding range of goods and services has been celebrated in economics since Adam Smith, here continued developments provoke unease. Why?

with Lacanian theory, structured into this discourse of health care reform that attempts to produce a social harmony, to keep scarcity at bay.

Lacan offers us an alternative to the bureaucratic/miserly domestication of scarcity and complementary hysterical reaction. The analytic operation treats the “knowledge” of health care reform discourse, in both its technical and hysterical incarnations, as if it were unconscious. Wright (1999) argues that the role of the analyst is to listen for moments in the discourse when familiar terms suddenly take on an uncanny appearance. The analyst uses these moments to interrupt the stream of discourse and to insert, however tentatively, a different interpretation of how things are or could be.²⁵

The ambivalent subjects of health care reform discourse—patients and providers—are at the center of this drama as both the cause of and (thwarted) cure for scarcity. The master signifier “scarcity” organizes and represents the desires of patients, providers, and society in a particular way. Yes, the inconsistencies in the representations of patients and providers that I identified in chapter II can be seen as moments where an alternative understanding might emerge. The ultimate aim of the analytic discourse is the generation of a new master signifier—a new way of organizing the spaces and subjects of care. In psychoanalysis the emergence of this new master signifier recasts the subject’s relation to the symbolic order and fantasy, allowing her to become unstuck. The new ‘master signifier’ is, according to Lacan, the unconscious product of the

²⁵ Derrida’s notion of aporia in textual analysis functions in much the same way. These moments of contradiction or circularity allow us to understand the set of unspoken assumptions that underlie the text.

analytic intervention (Lacan [1969] in Miller 2001). If this intervention is successful, the “new master signifier” appears as if it has always already been there.

Where might we identify these uncanny moments, these aporias in the context of health care reform discourse? Perhaps in those moments where the patient doesn't act like a rational/demanding consumer? Possibly in instances where the relationship between the patient and provider is one of cooperation rather than coercion? There might even be other actors, other agents of care lurking in the shadows of health care reform discourse who might fundamentally shift the terrain of the debate if only they could be heard. In surveying the health care reform debate, I have noticed at least three moments in the discourse that potentially challenge the obviousness of “scarcity”: patients with unexpected desires, providers who engage their patients in a different type of relationship, and finally the unexpected places where care is produced. Collectively, these different desires, relationships and places might serve to unsettle the basic assumptions that govern the debate, suggesting an entirely different way of understanding the economic dimensions of care. While there still might be limits in terms of the willingness or desire to produce care, they would no longer be understood in relation to a natural or inherent scarcity of care.

Uncanny Moments in Health Care Reform Discourse

Unexpected Desires: Patients at the End of Life

Skinner and Wennberg (1998) note profound differences in end-of-life care delivered to Medicare recipients in Miami, Florida and Minneapolis, Minnesota. Consistent with the findings in the Dartmouth Atlas of Health Care, more intensive care was positively correlated with per capita income. Medicare patients in Miami routinely received more care for the various ailments under scrutiny—more

bypasses and less drug-based treatments for heart disease—then their counterparts in Minneapolis.

Among Medicare patients hospitalized with AMI, stroke, GI bleeding, and cancer, we find no evidence that higher levels of spending translates into extended survival. But it may still be the case that people in high-intensity areas prefer the more intensive treatment. And while we do not know conclusively that people in such regions would prefer more intensive health care, we do know that patients living in other areas, if provided with information to make their own choices, generally prefer less, not more, intensive health care. Thus we conjecture on the basis of economic efficiency, Miami may fall short of Minneapolis. (20-21)

Skinner and Wennberg's study raises an interesting question about the desires of the patient. As Reinhardt (1997) and Grumbach (2002, 156) point out, patients in their last year of life consume most of the caregiving services in the United States. Skinner and Wennberg's study appears to suggest that end-of-life patients do not always prefer the most invasive (and therefore expensive) forms of treatment.

Skinner and Wennberg conclude with an argument for a standardization of Medicare-funded end-of-life care that focuses on pain alleviation rather than more intensive/invasive forms of treatment. Yet, do we not find here a more fundamental insight that directly contests the way we have been told to understand the patient (as an all-demanding consumer)? Here we have patients, in their time of greatest need, who desire less invasive/expensive forms of care yet, as both Etzioni (1991) and Mullen (1998) note, the sense of imperative urgency that surrounds the health care debate—to control spending or ration care—is predicated on the simple idea that patients, if given the choice, will always choose to consume more resources. Furthermore, as Skinner and Wennberg point out, informing the patient of their options/probable outcomes could play a significant role in the course of treatment they elect. This is not to say that patients never

make unreasonable demands. Rather it suggests that providers might engage with and possibly transform the desires of the patients in the course of their interaction.

Patient as Participant: Complementary and Adjunctive Care

In making their arguments in favor of consumer-driven health care reform, both Colie (2000) and Herzlinger (1997) note the rapid growth in alternative or complementary medicine. Most types of complementary medicine are paid for out-of-pocket. They see in the growth of this sector a strong argument for the free-market-driven reform of health care, reasoning that there must be something about complementary medicine that makes consumers want to pay for it. Herzlinger argues that the growth of this sector is a function of its consumer orientation—willingness to make house calls, for example, or to provide courteous low-cost services.

Complementary (alternative) practitioners are confronted with a unique challenge which stems from their exclusion from traditional insurance schemes. As we shall see in Chapter IV, alternative care providers are up against their patients' unexamined belief that only therapies covered by insurance are worthwhile. The fact that some approved services are "free" for the well-insured patient only makes the task of the alternative practitioner more difficult. Alternative practitioners frequently find that they must convince patients that the services they are providing are worth paying for. How can you convince someone that a holistic approach to weight management involving an exercise, diet, and a lifestyle coach is worth paying for when this same patient could simply consume a statin drug for "free" in the hope of avoiding the consequences of a sedentary lifestyle?

Both Herzlinger and Colie argue that complementary practitioners are forced to focus on customer service in order to compete under free market

conditions. They argue that this responsiveness and concern, set against the backdrop of conventional medicine, has allowed for the remarkable growth of this sector. However, many complementary practitioners argue that they are engaged with the patient not because they are being solicitous, but that effective diagnosis and treatment requires the patient's careful consideration and participation. Many types of complementary healing revolve around diet and lifestyle change (Ayurvedic medicine, for instance), while others engage the patient in a dialogue with the care provider about physical symptoms and the feelings and experiences of the patient (acupressure, acupuncture, and chiropractic, for instance). In this vision, the patient is not simply a consumer who prefers the type of "customer service" they can get from an alternative practitioner. Rather, they are a participant in a process that involves them in producing their own healing and well-being. Such an approach to healing challenges the depiction of the patient as a passive and needy consumer.

Different Places: Informal Caregiving

Even the people most committed to optimizing the "health care system" through the application of free market principles, such as Dranove, tacitly admit that there are elements of the care economy that are located outside of the market sector. Dranove points out that much of the cost savings achieved by MCOs in the 1990s related to finding ways to reduce the length of hospital stays. Undoubtedly this was partially an effect of technological innovation—for instance, the development of less-invasive procedures and refinements in the administration of anesthesia reduced hospital stays—allowing MCOs to favor (and pay for) outpatient treatment rather than procedures involving hospitalization (Dranove 2000, 43). Anders (1996), however, suggests 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 nursing staff to informal caregivers in the home. One could see this practice, “quicker and sicker” discharge, as a particularly pernicious form of privatization. However, it also brings into practice a range of caregiving places that are located outside of the debate.

In a groundbreaking study, Arno, Levine and Memmott (1999) set out to quantify the amount and value of informal elder care produced in the U.S. They analyze 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, 183). By assigning different hourly wage values to informal caregiving, from \$5.15 an hour to \$11.20 an hour, they estimate 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 (185).

The passage of the Older Americans Act Amendments in 2000 and the implementation of the Family Caregiver Support Act in 2001 are important steps towards recognizing the importance of informal elder caregivers. The Area Agencies on Aging, established with the passage of the Medicare/Medicaid Legislation in the 1960s, have been given responsibility for the disbursement of funds and administration of programs associated with these two more recent pieces of legislation. In a recent policy brief, the National Association of Area Agencies on

Aging (N4A) restated the magnitude and importance of the informal caregiving. While they noted the monetary value of such care they also discussed the opportunity costs associated with informal caregiving. The N4A estimates the average lost wages and benefits by those burdened by informal caregiving to be \$109 per family per day while MetLife Mature Market Group estimates “lost productivity to U.S. businesses to be \$11.4 billion annually” (N4A 2004). 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)

The N4A’s principal policy argument is that more support should be made available through the National Family Caregiver Support Act, to be administered through the various programs that currently compose the “patchwork” of support organizations. One is tempted to see in this policy statement a call for something more fundamental than simply increased funding levels. 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. They also 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. Conducting a series of extended informal interviews, Donelan *et al.* were able to gather extensive information on the intensity and complexity of informal caregiving. Tasks ranged in difficulty from assisting in daily activities—showering, toileting—to negotiating medical forms and administering medication.

In the course of their survey they noted something else as well:

One in four caregivers performing these tasks (administration of medication, bandaging, monitoring of home medical equipment) for someone who was hospitalized in the past year indicated that they were doing this work because the care recipient had been sent home from the hospital “too soon.”(226)

A significant number of respondents said they were given no instruction on the performance of more complex caregiving tasks (such as bandaging) and 12 percent of respondents admitted to making mistakes in the administration of medicines. 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, 231)

In Donelan's remark here, there is also the understanding that informal caregivers are uniquely motivated subjects—"beyond duty and privilege." While "duty" speaks of the coercive potential of social norms and "privilege" allows us to imagine an action that is undertaken because of its pleasure or prestige, what lies beyond this? What is beyond duty and privilege that we, apparently, have no name for? Coming up with answers to these questions might require of us a different way of understanding our relationship to the labors we undertake or, further, how we might understand duty and privilege. This in turn might lead us to question how other care providers—including those operating as paid laborers—experience caregiving. We presume that compensation is the major reason why health care workers operating in the paid sector do the work they do. What if we allowed ourselves for a moment to imagine that they, like informal caregivers, are driven to care because of something that is beyond duty, privilege, or even self-interest? This imaginative process would allow us to theorize the subjects of care and bring them into being.

Content in Search of a Form: Health Care in the Diverse Economy

The different desires, relationships and places discussed in the preceding section unsettle some of the fundamental terms that define the health care reform debate. Patients do not always want more care. Complementary medicine is not simply focused on customer satisfaction but in changing the relationship between provider and patient. Finally, caregiving is provided in a variety of spaces by unpaid actors who cannot be seen as rational utility maximizing agents. People on both sides of the health care reform debate appear to recognize the differing desires of the patients, the growing popularity of complementary medicine, and the massive size of the informal sector. However, these elements have yet to be

integrated into a truly novel approach to health care reform. It is at this point that I would like to take the risk of resuming the role of analyst. For Lacan the analytic approach revolves around a non-hysterical response to discourse. Rather than point to the insufficiency of a bureaucratic health care reform discourse—what Lacan referred to as University discourses—the primary mode is to listen to this expert discourse as if it were the enunciation of the analysand’s unconscious, to reveal that it is already pregnant with a different way of thinking.²⁶

All of the studies discussed so far suggest openings in health care reform discourses or, rather, an excess of meaning that is momentarily visible. These aporias offer us a chance to articulate an alternative vision of health care reform. The practice of the analyst is to use these momentary openings in the unconscious discourse of the analysand to interrupt the endless circuit of “efficiency” and the intractable stalemate of state and market. Through such interruptions, we might be in a position to suggest other ways of making sense of the health care, other ways of producing, allocating, and receiving care. These aporias allow us to glimpse a vision of health care taking place in the context of a larger economy, involving different actors and desires. As I will argue in subsequent chapters this more embracing economy of care potentially releases us from a scarcity based discourse of reform.

In the psychoanalytic process, the analyst listens to the fantasies of the patient, waiting for what Freud referred to as the uncanny moment in the narrative

²⁶ It should be noted that there are certain circumstances where a Lacanian analyst would make strategic use of a hysteric discourse when dealing with someone who has a perverse psychic structure. The goal of this intervention would be to get the pervert (a masochist who believes, for instance, that he is the desired object) back into an “ordinary” neurotic condition where desire floats from object to object.

(Wright 1999). Just as the uncanny element of a dream is the thread the analyst reaches for to unravel the terms of a fantasy, the recognition of the magnitude and (potential) importance of informal caregiving allows us to begin to see just how constrained our conception of care is. What if we were to focus national attention on what it might really mean to fulfill the terms of the Family Caregiver Support Act?²⁷ It may be that improving capacity to care for the chronically ill in their homes is as valuable a health care reform as any that might be conceived in a clinical setting. It might also be that people's capacity to live full and healthy lives might be more positively affected by redefining the length of the work week than by any advance in pharmaceutical technology. Seeing a new balance between work and life as a new approach to health care reform requires, in my view, a more embracing notion of the economy of caregiving.

Currently, this approach to reform exists in a state of potentiality. Interrupting conventional health care reform discourse is not the same as offering a substantive alternative imagining of how to reform care. To create a substantive alternative, we need to put these different desires, relationships, practices and spaces in a different theoretical context so that they might be linked together in new ways. Put differently, what if, in discussing palliative care, complementary medicine, and the role of informal caregivers, we have content in search of a new

²⁷ The danger here is, of course, that informal home care can also be invested with a fantastic meaning. It is reasonable to be concerned that emphasizing the size, value and importance of unpaid labor in producing care in households and other community settings will merely rationalize and accelerate the withdrawal of state support. At the risk of being read as a constellation in the "thousand points of light" or as a soldier in the "army of compassion," the point of highlighting informal caregiving is to shift the locus of antagonism in the health care reform debate. Limits on time, resources and emotional energy are as present in the household as they are in the hospital. There is, however, a difference in how we can imagine addressing these shortcomings. Rather than getting hung up on the question of how to allocate or pay for home care—since payment is not really an issue—we are in a position to ask what we might do at the point of production to ensure that home care remains vitally productive.

form? Lacan understood the end of analysis not as an end to signification/fantasy but rather as a reconfiguration of the analysand's relationship to these processes so they are no longer stuck in a way that causes them to suffer. Currently the U.S. is mired in an intractable debate about how to pay for health care—a debate which pits empathy against economism, “feminine” sentiment against economic reality. What if this new way of thinking about providers, patients, and spaces of care gives us a way around this deadlock?

Freud saw the end of analysis in a slightly different way that might be of use to us here. In his neurotic patients Freud saw the suffering caused by the “prohibition of the impossible,” the incest taboo being the classic example (Žižek 1991). Here of course, what is being regulated is not the sexual prerogative of adults but rather a son or daughter's early erotic desire for their mother or father. The “prohibition of the impossible” fixes the subject in neurosis by tantalizing him with the idea that an un-alienated existence is present for others—his father—but not for himself. To put this in more general terms, prohibitions of any sort incite desires. They not only install the forbidden object as the unobtainable/desire, but direct the subject's attention away from other sources of possible satisfaction. The analysand must learn through analysis that he, as the son, could never be a sufficient love object for his mother. In coming to grips with this, the analysand also recognizes that there is also a lack in the mother (and father) just as there is a lack in himself. This recognition of universal lack is what finally permits the patient to pursue such satisfaction in love and work as he may find. When the subject is no longer fixated on the prohibition of the impossible, Freud reasons that he is now permitted to be able to do what is necessary (Byrne 2003).

Zupan i (2000) sees in the post-analytical subject's recognition of universal lack a sort of paradoxical freedom.

Currently we are confronted with a prohibition of the impossible—care is seen as a social cost that must be contained because the demand for care is infinite. Of course it is impossible to deal with infinite demands. The drive to contain costs and optimize delivery is a function of this belief in infinite demand.²⁸ This drive takes on a repetitive, circular quality because there is always more fat to trim. To get beyond this we need to recognize that patients are not consumers like the rest of us; they are an unfortunate 10 percent of our population that happens to be ill (Reinhardt 2000). Recognizing this simple fact allows us to perceive that we are not confronted with an impossible “infinite demand” but with a finite demand from a particular group of people. Just as the analysand's recognition of “ordinary lack” creates space for actual satisfaction by permitting the necessary, seeing an “ordinary need for care” creates a space that permits to do what is necessary—to provide the care that is needed under the conditions of changing/changeable limits. Perhaps it is only through a shift in “attitude” that we will be able to bring to bear our creativity in the use of social resources to produce care for the people who need it.

Theorizing the Diverse Economy: The Rethinking Economy Project (REP)

It is easy to imagine informal caregiving as a mere supplement to care provided in the clinical setting, not as place where “real” care takes place. Likewise, even the name “complementary medicine” suggests the adjunct status of

²⁸ If Stavrakakis (2003) is correct that today's consumerist cultures cultivates and depends upon the infinite metonymical shifting of desire: from one object to the next, naming the patient a consumer has powerful effects on how we conceive of their desires.

chiropractors, acupuncturists and other alternative providers in relation to “real” medicine. Finally, the desires of gravely ill patients could be seen simply as a “special case” that leaves unchallenged the assertion that the patient is infinitely demanding. Yet we can see in these uncanny desires, relationships and places a challenge to the fundamental presuppositions of health care reform discourse.

It could be argued that each of these uncanny elements could be incorporated into the conventional discourse of health care reform. Indeed many geographers argue that informal caregivers are already asked to shoulder an increasing portion of the care burden (Staeheli 2005). From this perspective, further “recognition” of the importance of informal caregivers is likely to result in their further exploitation. Likewise, one could easily imagine that the only lesson from Skinner and Wennberg’s study is that there are additional opportunities for cost reduction that are currently unexploited. Finally, complementary medicine is already being seen as the “lead sector” in free market health care reform. We are in danger of these uncanny moments in health care reform discourse becoming part of the same rather than an opening into the new.

If these desires, practices, and spaces are to avoid being placed in a subordinate position, if they are to escape being swept up in a discourse of optimization and rationing, then we must come up with a new context for understanding them. Doing so might allow us to imagine different ways that informal caregiving and complementary medicine might relate to drug therapies or other sorts of conventional interventions. Creatively reconsidering how these different aspects of care relate to one another might lead to a completely different notion of health care reform. We might generate an approach that breaks out of

the circular drive to “optimize” care delivery by constraining demand and controlling costs.

This dissertation draws its inspiration from the work of the Community Economies Collective (CEC), of which I am a member, and the social theoretical perspective of J.K. Gibson-Graham. The goal of the CEC, as it has evolved over the last five years, has been to produce an alternative imagination of the process of economic development. As I shall describe in the section that follows, this alternative approach is based on an enlarged conception of economy and the variety of ways that different elements of this economy might be brought into beneficial relation with one another through the process of development. For example, in what way might formal and informal sectors of the economy interact? Ultimately, the idea is to shift the way regional economic development might be practiced when it is freed from the idea that communities are hostage to the demands of large capitalist firms or “the global economy.” In order to follow the work of CEC and re-conceive health care reform as a type of (economic) development it is necessary to go into some detail to explain my involvement in the CEC and its work. I will start by reviewing the theoretical developments that led up to and inspired the Rethinking Economy Project (REP). This will be followed by a description of the REP and its four stages. I will conclude by situating the work of this dissertation in relation to the REP.

Confronting Capitalocentrism: Origins of the CEC and the REP

A principal challenge to the CEC in its various research projects has been to represent the radical potential of what already exists, to illuminate what is already known to exist in a way that strips away its familiarity in order to see new possibilities. The insights of feminist and Marxian theory as it has been developed

by Association for Economic and Social Analysis (AESA) have played a decisive role in the process of re-imagining the economy—making the canny into the uncanny.²⁹ Likewise, it draws upon the work of a host of scholars and activists operating in many disciplines and spheres who describe mechanisms of exchange (e.g. gift giving), the role of illegal and informal economic activity, barter economies, indigenous economies, etc. All of these scholarly, empirical, and practical efforts have contributed to theoretical rethinking(s) of the economy as a space of heterogeneity. In 1999 CEC members began a research project whose aim was to empirically validate the notion of economic difference on a regional scale in the hope of enlivening an alternative approach to economic development.

Feminist Beginnings

Feminists have long argued for a greater recognition of household and community—the feminine sphere as the sites that creates and sustains life. Scholar-activists such as Waring (1984) have long maintained that childminding, cooking, cleaning, and elder care are labors to be valued just as surely as that which goes on in offices, mines, and foundries. More recently, other scholars have attempted to quantify the size and value of economic activity in households, arguing that goods and services produced in households should be counted in national economic accounts. Ironmonger, for example, argues that the Gross Household Product should be added to the Gross Domestic Product to produce

²⁹ Wright (1999) points out that one meaning of “canny” is homely—ordinary, plain, even ugly. The role of the uncanny in art—let us take poetry for example—is to take ordinary words and by creative effort illuminate an unexpected meaning. Is not feminism’s attempt at transforming the meaning of everyday domestic activity an uncanny exercise? Isn’t this an effort to make the homely unhomely, to render it momentarily unfamiliar?

the Gross Economic Product, the sum total of the value of goods and services produced in a year (e.g. Ironmonger 1996, Folbre 2001).³⁰

As important as these points are in representing the economy, there is another point not to be missed. As Gibson-Graham (2003c, 146) observes, feminists have been arguing against the exclusion of women and the household sphere from the purview of modern economics since its inception as a discipline.³¹ The glaring obviousness of Waring's argument forces us to conclude that household labor is not invisible or simply unrecognized but rather that it is disavowed. In psychoanalysis the disavowed can be acknowledged, even venerated, while at the same time it is taken for granted or even subjected to common abuse as the subject acts as if it were unimportant. For precisely this reason, Gibson-Graham (2003c) argues that there must be a politics of feminism that goes beyond a politics of "visibility." Something else is required, an intervention at the discursive level that re-conceptualizes the terrain of economy rather than simply adding in women's labor. What is needed is a new concept of economy that is at once heterogeneous and flat—recognizing the multiple sites of economy without ascribing priority to one and disavowing the significance of others.

³⁰ Other scholars behind Redefining Progress (RP) <http://www.redefiningprogress.org>, extend Ironmonger's argument even further. When these goods and services are supplanted by market based equivalents—daycare and eating out—these should not be thought of as an expansion of the market sector of the economy but as a substitution. Likewise, they argue that remedial economic activity—toxic waste clean ups, crime—should be counted as costs.

³¹ According to Gibson-Graham (2003c), the modern concern with commercial economic activity began as mercantile activity in the age of exploration (1500s) presented both a threat to traditional feudal authority of the nobility as well as an opportunity in the form of additional revenues that might accrue to the state.

Class Difference

This dissertation, in reflecting on the potential of informal caregiving in households, brings up the larger issue of how the economy is defined, how this definition works to limit our understanding of health care, and what alternative understandings might emerge if we were to think differently. The notion of household economics and the importance of informal caregiving carries with it the suggestion that there may be other economic spaces, practices, and other differences that are currently invisible and should be brought to light. Conventional economists (and many Marxists) confine their conception of the economy to the formal or market economy. For many Marxists, work in households (and other community-based social sites), to the extent that it is recognized, is regarded as the site of “reproduction.” Rather than being seen as sites of dynamic economic activity—with their own struggles, challenges and possibilities—reproduction fixes the meaning of the work of the household (and these other sites) as a subordinate condition of existence for productive economic activity.

Gibson-Graham (1996) argues 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 1996, 6)

Gibson-Graham argues 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,” it becomes synonymous with the economy as such. Table 3.1 is a way that we have come to represent the singularity of capitalism.

Transactions	Remuneration	Organizational Form
MARKET	PAID	CAPITALIST

Figure 3.1: “The Economy”

Capitalocentrism insists that capitalist firms employing wage labor to produce goods and services for a market are the economy. From this perspective, when we speak about any of these things—labor, markets, firms—we know we are talking about Capitalism. It is this metonymical linkage between these three elements that makes Capitalism both the species and genus of the economy. While it is ironic that Marxian theory has played a decisive role in creating this very idea of Capitalism’s omnipresence it is perhaps unsurprising. Marx believed the purpose of his theoretical intervention was to reveal the exploitative dimensions of the capitalist class process, a class relation that he saw as having a growing importance in European society with the collapse of the traditional “feudal” order. In addition, many Marxian theorists have imagined that Marx’s class categories—slavery, feudalism, ancient (self-employed), capitalism, and communism—describe a social evolutionary arc with communism being the highest stage of social development. In this tradition the important thing becomes the study of the

cataclysmic circumstances and crises that propel history forward from one stage to the next (Norton 2001). Gibson-Graham (1996), building on the work of Resnick and Wolff (1987) and others scholars in the AESA school, see Marx's class categories not as a historical progression but as a typology of difference. In the same way that feminist economists remind us that the formal economy is not the only economy, Gibson-Graham (1996) employs this Marxian typology to show that no society is uniformly capitalist.

Those operating within the AESA tradition distinguish among the class processes described by Marx—communism, capitalism, independent (ancient), feudalism and slavery—by focusing on the conditions under which surplus wealth is produced, appropriated and distributed (Gibson-Graham, Resnick and Wolff 2001).³² In exploitative class processes—capitalism, feudalism and slavery—those who produce wealth through their labors are not its first appropriators. Capitalism employs wage laborers in the production of goods and services. A culturally/historically determined portion of the net product is returned to the laborer in the form of a wage while the rest—the surplus—is appropriated by the capitalist board of directors. The board of directors must pay the interest on loans, rent, and other expenses while exercising some discretion over the remainder—what conventional economists call “profits.” In non-exploitative class processes—communal and independent—the productive laborers are themselves involved in

³² As Madra (2006) notes, there is a range of positions that can be taken in relation to AESA's theoretical insights. There are some within the school who argue that the actualization of the Marxian project depends upon a political commitment to the belief that only those involved in productive economic activity in a particular location should be involved in receiving the surplus that accrues from that activity. Others within the school argue that “non-exploitative” class processes are those that include productive laborers but do not necessarily exclude the involvement of non-producers in the appropriative moment.

the process of appropriating the wealth that they produce. Class analysis both allows us to understand the dynamics of exploitation and puts us in a position to imagine what difference it might make if a firm (or other process/site) is run without exploitation.

From AESA's perspective all of these class processes could be at work in any given society, including the present day U.S.³³ One important thing to keep in mind is that AESA's notion of class analysis can apply with equal facility to sites that are not producing goods and services for exchange as commodities. Goods and services produced in a household may be produced under slave, feudal, independent or communal conditions depending upon who produces and appropriates the wealth of use values. A contemporary "traditional" household would be considered feudal in class terms because the father appropriates the surplus wealth produced by the wife in the form of cooked meals, cleaned laundry, and kept home while he himself may not be involved in the process of their production. From AESA's perspective, slavery may also be seen to exist in the contemporary U.S. because there are laborers who operate without freedom of contract, whose product is appropriated in its entirety, and whose bodies are effectively the property of their owners. Prisoners in the United States who are

³³ Given this theoretical orientation it becomes another matter entirely to say that one class process—let us say capitalism—dominates in a particular society. If, from AESA's perspective, class analysis can be performed synchronically as well as diachronically, then it would be a matter of empirical investigation to determine which class process was most prevalent in any given society. To make matters more complicated it is entirely possible that someone might be a wage employee in a capitalist class process during the week, a self-employed independent on the weekend, and a feudal appropriator in his own household. Given that each individual might be involved in multiple class processes, the matter of gathering empirical information about the extent of any given class process might become infinitely more complicated.

compelled to engage in goods and service production find themselves in this position as well.³⁴

Taken together, feminist theory and AESA's approach to class analysis allow us to theoretically disrupt capitalocentrism by positing the existence of spaces of production, types of labor, and exchange that are outside of and distinct from those linked metonymically to capitalism.

Transactions	Remuneration	Organizational Form
MARKET	PAID	CAPITALIST
nonmarket	unpaid	noncapitalist

Figure 3.2: The Economy and its Other

Other Sources of Heterogeneity in the Economy

Other disciplines and scholarly efforts have complicated and enriched our understanding of noncapitalist economic space, building on the insights of feminist and Marxian thought. Economic anthropologists and informal sector theorists have documented both the extent and importance of informal production and nonmarket exchange that take place in a variety of noncapitalist social spaces across the globe (e.g. Gudeman 1990, 2001). While Gudeman's work is focused on

³⁴ It could also be argued that other categories of workers are or have been in a slave class process. Ross Weiner (2001) argues, for instance, that baseball players prior to the introduction of free agency were effectively well paid slaves, existing effectively as the property of their team

a country in the so-called periphery, other scholars have documented the importance of these same informal economic structures among the industrialized nations. Sociologists have documented the size and importance of the informal sector in Europe, the Soviet Union and, more recently in the post-Soviet states (Mingione 1991; Shanin 1988, 1999; Pavlovskaya 2002). Others have studied the role that alternative currencies play in creating and sustaining local economies and communities (Williams, Aldridge and Took 2003). Building upon these insights, the CEC sought to generate an open-ended representation of the community economy. See figure 3.3.³⁵

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
MARKET	WAGE	CAPITALIST
ALTERNATIVE MARKET Local trading systems Underground Barter Co-op exchange Alternative credit	ALTERNATIVE PAID Cooperative Self-employed Indentured In kind	ALTERNATIVE CAPITALIST Environmental ethic Social ethic State capitalist Non-profit
NON-MARKET Household flows Gifts Gleaning Indigenous exchange Theft Government transfer	UNPAID Volunteer Housework Neighborhood Family care	NON-CAPITALIST Communal Independent Feudal Slave

Figure 3.3: The Diverse Economy

owners. Likewise, soldiers operate without freedom of contract for the duration of their service and they are also explicitly regarded as government property.

³⁵ We also sometimes refer to this as the “nine cell diagram.” The difficulty here is that one is tempted to read the diagram as a matrix or to imagine that the alignment that connects the capitalism/wage/market runs consistently throughout the diagram when, in fact, any of the organizational forms on the right hand side could engage in any of the processes of exchange listed on the left hand side.

The “nine celled diagram” was really an elaboration of the preceding figures. The top portion of the diagram represents the economy as it is usually conceived (figure 3.1). The bottom portion of the diagram contains the “others” of market exchange, capitalist firms and wage labor from figure 3.2 as well as an intermediate category which, blurs or undermines this binary opposition. In this table our assertion is that just as every economy has goods and services exchanged in a market economy as commodities, there are also non-market types of exchange—the flow of values within a household, gifts, indigenous systems of exchange, government transfers (e.g. welfare payments), and even theft. Just as non-market exchange is present in every economy so too are alternative exchange mechanisms—barter networks, illegal markets, and alternative currency systems—present in most economies. If market exchange is motivated by self-interest and the gift giver by altruism, this third category suggests that there might be still other motivations for market exchange. Some barter networks are motivated by convenience and a chance to avoid tax liabilities, for example the commercial barter networks amongst people in the building trades, while other alternative exchange systems are guided by a conscious ethic that tries to use market exchange to satisfy needs and to produce a sense of connection or community. One of the important effects of this figure is that it deconstructs the opposition between self-interest and altruism, between gift and market exchange, through the introduction of this third category.

The diverse economy diagram performs a similar deconstruction in relation to firms. Capitalist firms are defined as firms that employ wage laborers who do not receive (appropriate) the wealth they produce or make decisions about what to do with that wealth. While this arrangement describes the class organization of

most firms operating in the U.S., it is by no means the only class process present. While the United States only has three hundred recognized worker cooperatives at present, this alternative organizational form has grown considerably since the 1980s in the U.S. and more rapidly in other places around the world (Craddock and Kennedy 2006).³⁶ In worker-owned firms, the people who produce goods and services in these enterprises are also the first receivers of the wealth generated through their exchange. Likewise, as Hotch (2000) argues, millions more are engaged in an ancient or independent class process (self-employed). (This class process might be important to consider in relation to health care reform since this describes many of the people who work in the alternative/complementary medicine.) As with exchange, the diverse economy diagram adds an intermediate category in relation to organizational form. It is important to note that there are alternative capitalist businesses that operate according to the so-called “triple bottom line.” These firms operate with social and environmental concerns as well as profitability in mind. Like capitalist firms, nonprofits or state-run enterprises may employ wage labor and have non-laborers in charge of surplus appropriation and distribution. A non-profit enterprise such as a public hospital, for instance, might be charged with a social mandate that takes priority over “profitability” and further there may be a degree of public or community oversight that makes sure that the social mandate is fulfilled. It is here that we see the potential of this diagram to describe not only economic difference but also struggles over how to organize the production and allocation of resources, how resources should be consumed and

³⁶ The modest growth in worker cooperatives must be set against the backdrop of a much more significant trend—the growth of employee owned companies. While ESOPs are typically capitalist in their organizational form Alperovitz (2004) estimates that there are presently 11,000

under what conditions needs should be met or even what resources in the community might provide support. In short, the diverse economy diagram represents the terrain upon which these struggles and antagonisms take place. It is where the community is constituted.

Finally, while receiving a wage in exchange for labor is one form of compensation, in the diverse economy diagram there are many types of labor for which no compensation is given. While unpaid labor may be largely thankless or merely “expected” (as is the case with feudal unpaid labor in the household) other people performing unpaid labor may receive considerable recognition from the community that benefits from this work.

Following the logic of the diagram each of the class processes corresponds with its own particular form of compensation. Worker owners in communal enterprises may receive a wage, the level of which they themselves determine, often with full cognizance of the limitations placed upon them by the pressures of a competitive market place. Some self-employed people may compensate themselves for their long hours of labor at a relatively low rate while others may use the freedom of being their own boss to work less. Compensation, whether it is “recognition” for volunteers or a collectively determined wage, is from this perspective a site of antagonism, struggle, and ethical deliberation.

The Diverse Economy diagram functioned for members of the CEC as a way of making sense of the economy as a heterogeneous topology. Its diversity is not simply the different organizational forms, mechanisms of exchange and modes of compensation but also a heterogeneity of values, struggles, and ethical

firms in the U.S. owned by their employees and that eight million worker-owners are involved in

deliberation. While we see the table as the logical consequence of our commitment to non-capitalocentric thought, it also became a new way to conceive of a politics of economic transformation or development. With the help of the diagram it becomes possible to speak of non-capitalist development or non-capitalist health care reform. These political projects are not informed by an impulse to eliminate the capitalist class process or to replace it wholesale with something else. Rather, the economy becomes the site of ethical practice that connects different coordinates in the diverse economy—including capitalist firms—in a way that corresponds with a struggle to define and enact values. This was the motivation behind the REP.

Four Stages of the Rethinking Economy Project

Beginning in 1999, the CEC launched the REP. This action research project involved four stages and focused on documenting the hidden, alternative, and non-capitalist economy in the region where the University of Massachusetts is based—the Pioneer Valley of Western Massachusetts. Under the direction of Julie Graham, the REP involved a number of graduate students and associated faculty who met regularly, long before starting the research project, to discuss how we might use the project to “empirically” validate J.K. Gibson-Graham’s assertion that the U.S. economy is a heterogeneous terrain, that the U.S. is not a “capitalist country.”³⁷ The first stage documented the dominant conception of economic development as it was understood by planners, elected officials, representatives of local Chambers of Commerce, and community development corporations. In the

ESOPs.

³⁷ “Empirical” is not a term that can be used in a straightforward way from a poststructural perspective. This project involved the discursive constitution of the very artifacts we expected to

second stage, with the help of local progressive organizations, we recruited community researchers to document economic activities that fall outside of the purview of the dominant economic imaginary by means of in-depth semi-structured interviews. The third stage involved the transcription and analysis of these interviews and the development of case studies that looked for economic difference within particular “sectors.” In the fourth stage of the project we devised a series of popular presentations to report back the findings of the REP to the Pioneer Valley community. This stage is ongoing and involves us in trying to imagine and enact a non-capitalist approach to economic development in collaboration with others in the Pioneer Valley of Western Massachusetts.

Stage 1: Economic Genealogy

The initial goal of the project was to document the notion of economy and the process of development that operates locally in the Pioneer Valley. Following Philo (1992), we conceived of this phase as a spatial genealogy of development discourse. Reading through planning documents from cities like Holyoke and Springfield, towns like Amherst and Northampton, and the rural hinterlands, allowed us to see connections between academic theories of development and how development was imagined in local planning offices, business associations, and government agencies. On the one hand, for example, Holyoke’s planning office seemed captured by the older language of “export base theory” while the Pioneer Valley Planning Commission, the City of Springfield, and the town of Amherst all spoke of the economic development in terms of industrial clusters. On the other hand, economic development discourse in the Pioneer Valley was

encounter in the course of our research. In fact, the “nine cell diagram” was continually redefined

characterized by particular regularities as well. All of these different discussions of development, for example, do not appear to regard households as sites of significant economic activity; instead they are seen as dependent upon a vital market sector.

Our next step involved conducting two focus groups with development experts throughout the region. These sessions revolved around a set of questions that were designed to get the development practitioners to think about the state of the Pioneer Valley's economy as well as gathering their reactions to our research agenda. The sessions were professionally recorded on video. As expected, in conversation many regional development authorities, political representatives, and even spokespeople for organized labor spoke of the economy in terms that were very familiar to economic geographers. Development is reduced to process of attracting, accommodating, and retaining large capitalist firms or clusters of smaller firms in the same industry while the fates of households, neighborhoods, schools, churches, and non-profit hospitals were held hostage to their needs.

One person we spoke with Rick Brown, President of the AFL-CIO, summed up the state of the local economy with a single phrase uttered despondently and accompanied by a chorus of agreement: "It's a global economy, obviously." The way in which this statement was made—with the half apologetic and half authoritative addition of "obviously"—made us appreciate Derrida's (1991) notion of the present-absence. Capitalism as a term was consistently a present-absence in our conversations with local development experts as well as in their master plans and policy statements. Though often unmentioned, the figure of capitalism was

over a period of conversations.

always there as a specter, made present as an unseen but all-powerful force or logic. For instance, the 1996 and 2001 regional plans repeated the assertion that not only is the (capitalist) economy global but in the “post-cold war era” it is now without a rival. It was clear that there was an unspoken or assumed equation of capitalism with the global economy as such (Gibson Graham 1996; Graham, Healy and Byrne 2002).

Like their left counterparts, local economic development practitioners—even progressive ones—effectively believe that (large) capitalist firms employing wage labor in the production of goods and services for exchange in the market place is the most important (if not the only) economic process. Regions that can attract or retain large capitalist firms, preferably engaged in manufacturing (e.g., Information Technology, biotech) or other sectors with export markets will prosper while those that fail suffer the consequences of not integrating into the global economy.

Towards the end of the session in each of the two focus groups we conducted we asked our expert informants about a recent study of the arts economy in the town of Northampton, Massachusetts—a former manufacturing community and home to Smith College, which has successfully pursued a tourist/arts economy-led redevelopment effort. This study, conducted by Robert Nakosteen and published in *Massachusetts Benchmarks* (1999), pointed out that the size of the Northampton arts economy was perhaps underestimated because much of its activity takes place (untaxed) in the informal economy.

While we generally look to numbers to spell out economic impact of any industry, and often times they do, there are things the numbers don't catch. Why don't the arts register on the Dun & Bradstreet or the Division of Employment and Training data screens? Because many artists aren't employed in the traditional sense. They don't

work for firms that pay wages, taxes and unemployment insurance. But they are working artists nonetheless. (Nakosteen 1999, 4)

We asked focus group participants to think of what else might be taking place in the region outside of the formal economy, beyond paid labor or export-oriented firms that might be enrolled in the process of development.

To our amazement, in both focus groups participants came up with examples of economic activity outside of the market/wage/capitalist economy (CEC 2001a). Some of these activities, like the arts sector, were considered worthy of support while other examples, the drug trade, could not be seen to contribute to economic well-being. Likewise, in the course of the conversation it became clear that public goods, like education and what might be thought of as “civic spaces,” were sites of economic activity, though they were not “capitalist” in any precise sense. While this conversation momentarily opened the space of the capitalist economy to include its non-capitalist other, one of our focus group participants, Allan Blair from the Western Mass Economic Development Council, ultimately sought to circumscribe its significance. Essentially, his position was that it’s nice to have arts and culture but none of those things would exist without a base in industry that serves extra-regional markets. In this remark we saw yet another instance in which the momentary visibility of the diverse economy gives way to its disavowal. For instance, in the course of discussion it was noted that basic education plays a vital role in the socialization of workers while higher education is the wellspring for entrepreneurial initiative. Education, like the household (and health care), plays a complementary role in reproducing the “real” economy in export-oriented industries.

Here, however, the mainstream development discourse finds itself in an epistemological catch-22 that was readily evident in the transcripts of our focus groups. On the one hand, education—like the arts—will only be in place if you have an economic base that supports it. Education, vital communities and cultural amenities are the effects (the payoff) of successful development, signs that your region “has arrived.” Yet, at another point in the same conversation, one of our experts observed that you cannot attract entrepreneurs without cultural amenities and that you cannot cultivate a work force without a good public school system. When these statements are read together it’s as if mainstream development discourse is saying only already successful regions can be successfully developed—exposing a major inconsistency in conventional economic development practice.³⁸ It acknowledges the existence of what we are thinking of as the non-capitalist economy (usually regarding it as cultural or non-economic)

³⁸ The city of Springfield in our region reached a new low in the summer of 2004, requiring the state to pay out \$50 million in order for the city to be able to pay for basic services (fire and police). One of our informants, Henry Thomas from the Urban League, had this downward trajectory in mind when he argued (in 1999) that all the economic development planning in the world won’t help Springfield if schools and basic services aren’t attended to. This drew a chorus of agreements from the other participants. It was at this point that the labor representative, Rick Brown, made an interesting observation. He recalled a Frontline broadcast he had watched a few nights before about a suburb of Atlanta named Conyers, Georgia. Conyers had been in the news the previous spring for a school shooting but the documentary focused on another set of disturbing events that had happened prior to the shooting.

The citizens of Conyers were mostly recent arrivals drawn to Atlanta by the then booming high tech sector in the region. Frontline’s cameras panned up and down the streets of Conyers showing the lavish 3,000 square foot homes that can be purchased by people working upwards of 70 to 80 hours a week. The camera then cuts to scenes of young people raising themselves, attempting to socialize in strip mall parking lots and one another’s homes. We learned that it was in this “upper middle class” white suburban setting that public health officials witnessed one of the largest outbreaks of syphilis and that, more shockingly, the center of the cluster was a group of twelve to fourteen year old girls. The point that Rick Brown echoed from Frontline was that this was an economically successful community where children, deprived of their parents by long hours of work, were essentially raising themselves. The struggle of poor communities like Springfield to secure some sort of civic and community infrastructure is unsurprising to many of us. The level of anomie and the absence of community life and amenities in communities like Conyers with their good jobs, tax base and school system is shocking. This suggests to us that there is more to development than economic growth. Successful development must involve more than attracting and retaining firms that operate in lead sectors of the market economy.

and accords it some significance in reproducing or complementing the economic activities of capitalist firms.

Through genealogical investigation we found that local economic discourse development was marked by both regularities and exclusions. The need for economic growth in an era of globalization was a definite regularity as was the unspoken assumption this involved increasing the amount of capitalist economic activity. We also found that non-capitalist spaces—that which is excluded from mainstream development discourse—ultimately provided a supplementary function. All of our focus group participants acknowledged that schools, homes, and other “non-economic” institutions are crucially important to the process of economic development. However, the function of this “acknowledgement” in conventional development discourse is to absolve those that speak it from having to think about what it might mean to support what is variously called the “third sector,” or “civil society.” Here the psychoanalytic concept of “disavowal” proves salient once more—while success reflects the merits of the development practitioners alone, failure is an outcome of “circumstances” beyond their control.

³⁹

³⁹ On the other hand their legitimacy and authority as development experts—those who can successfully auger the demands of the economy and assuage them—depends upon the separation of the economic from the non-economic. Acknowledging how the economy depends on the so called non-economic sites—household, community—carries with it the risk that perhaps other people could be involved in the process of economic development. It also should be noted that there is a more violent version of this disavowal. For instance, as Jamie Peck (2006) has argued Neoliberal think tanks like the Manhattan Institute popularized the idea that it is the moral depravity of the “underclass” itself that is to blame for the failure of urban renewal. The poorly educated or economically marginal, far from being victims of circumstances, are culpable for the economic failure of the city.

Stage 2: Charting the Diverse Economy

Stage 2 of the REP began by recruiting community researchers from various organizations throughout the Pioneer Valley. Our aim was to get these community researchers interested in doing qualitative research on the Valley's hidden, alternative, and non-capitalist economies. We contacted as many organizations in order to get people whose informant base might be different in terms of race, income, age, urban vs. rural settings, etc. We ended up with seventeen community researchers who satisfied these demographic and representational concerns but, more importantly, who seemed open to and interested in the work that we were trying to do.

We ran three orientation sessions in order to introduce our community collaborators to the hidden, alternative, and non-capitalist economy.⁴⁰ One of the most important tasks of the training was to disabuse them of the notions of economy that they held in common with our expert informants. For many of our community researchers, the economy was a mysterious or all-powerful force that presented them with a choice between submission or marginalization, impotent rebellion or the hope that somehow they themselves and the people in their community would find their niche as employees.⁴¹ We used different visual representations of economic difference in order to catalyze the process of re-imagination. Figure 3.4 is a visual image that proved to be particularly important.

⁴⁰ The first two of these sessions were with adults recruited from across the valley while the third session was conducted with a group of high school students (all young women) at the Urban League center in Springfield, Massachusetts.

⁴¹ In other words, many of our community researchers had the same relationship to “the economy” as our expert informants even if they expressed it in a resentful or pessimistic way.

We used the “iceberg” to show the relationship between the recognized economy and the hidden and alternative one.



Figure 3.4: The Diverse Economy as Iceberg⁴²

This image proved very powerful in realigning the perceptions of our community researchers. Many of them used this image when doing the work for which they were hired—conducting semi-structured in-depth interviews with their friends, neighbors and acquaintances. Our community researchers used the iceberg to prompt their informants into talking about their lives both inside and outside of any “formal” economic activity they might participate in.⁴³

⁴² The iceberg was developed by my REP colleague, Ken Byrne.

⁴³ There is an irony here, however. One of our community researchers, “Paul” (CEC 2001), summarized the meaning of the iceberg with the following observation. It is only because all of these other things take place in the community, the bottom portion of the iceberg, are what make it possible for the regular economy to float above the surface of the water. Here our visual metaphor seemed to court the risk of reproducing the very relational logic that we wished to challenge—that of capitalist reproduction.

The diverse economy diagram presents us with a similar challenge in the sense that it still ascribes a certain visual priority to the separation between the market/wage/capitalist economy and everything else. The challenges that both of these representations present us with are, in a sense, a reflection of the power of capitalocentric thinking. On the one hand we all know that “capitalist” businesses cannot operate in the absence of the communities in which they reside—they are embedded—on the other hand we still act as if they are inherently “special” or privileged economic sites. In my view, this merely represents the intellectual and political challenge before us.

The community researchers conducted seventy-two in-depth semi-structured interviews that focused on people's economic lives, including wage employment and participation in household and community economic spaces. Interview lengths ranged from twenty minutes to nearly three hours. Some of these interviews were with individuals and groups that were self-consciously working towards producing an alternative economy. There were also interviews with individuals whose religious convictions directed them towards volunteer work and generosity both inside and outside of their immediate family and household, while others engaged in volunteering purely for the satisfaction that it produced. A few of the interviews focused on individuals with businesses that were communal or independent. Still others focused on questions related to capitalist businesses governed by a social or environmental ethic.

What we got back from the community researchers were interviews that represented different economies defined by the places and relationships within them as well as potential conflicts, antagonisms and desires and ethics expressed there. These multiple economies—the household economy, the gift economy, the volunteer economy and the economy of alternative businesses—were composed of various elements from the diverse economy. While some of the interviews uncovered unethical, illegal, or destructive economic activities, the overwhelming majority of interviews focused on the generosity of the interviewees, their interdependence with family and community, and the ethical motivations behind their economic activities. For our community researchers it was this process of giving that appeared to actually generate the connections of community.

For the most part, the academic researchers did not anticipate these multiple economies as a research outcome. In some sense, our community-

researchers (mis)recognized our desires when they returned from the interview process with interviews that focused on people's generosity, the practices of volunteering, and the way that these things intermingle in the intensity of complex household economies. In retrospect we realized we assumed that they, like us, would be most interested in the role that the informal economy and non-capitalist businesses (collectives, sole proprietorships) might play in an alternative practice of development. There were a few interviews that did focus on market-oriented businesses but these were primarily progressive capitalist businesses that operated with a social and environmental ethic.

Stages 3 and 4: From Research Outcomes to Alternative Development

Over time we came to recognize this moment of divergence between our agenda and those of our community collaborators as an instance of productive misrecognition. The third stage of the research project involved the transcription and analysis of the interviews conducted by our community researchers as well as conducting new interviews of our own that focused on particular communities, economic sectors, and institutions. These follow up interviews drew inspiration from the multiple economies of generosity that captured the interest of our community researchers.

The process of transcription and continued research played an important role in the fourth stage of the REP where we put together a public presentation of our findings. In our initial public presentation, delivered in June of 2001, and in the many we have given since, we have argued for a vision of non-capitalist development that combines these various economies of generosity with our interest in fostering community-oriented collective (non-capitalist) enterprises (CEC 2001b).

This vision of development is neither meant to complement (and ultimately be subordinated to) conventional “capitalist” development, nor is it imagined as its replacement. Rather, as Özselçuk and Madra (2005) argue, we see in the non-capitalist elements of the diverse economy a set of coordinates that could be brought into beneficial relation to one another, guided by an ethical practice that we have come to call building the “community economy” (Gibson-Graham 2003a, Gibson-Graham 2003b). The community economy is not for us a positivity that definitely resides in the interaction between, for example, a community-owned business and a non-governmental organization. Rather the community economy is a term that we use to describe the moment where the relationship between various elements of the diverse economy can be (re)connected or articulated with yet another element.

We might be tempted to add here that “economy” has gone from being a monolithic entity that is spatially invariant—operating according to a uniform logic or process of development—and has become instead (finally) part of the human landscape, the landscape of difference, contingency and possibility. If the economy were only a homogenous terrain that proceeds according to an invariant logic there would be no meaningful way to speak of choice, freedom or ethics in relation to economic space. It is precisely through the assertion of difference and undecidability that the economy can become a space of ethical deliberation—what do we want in the face of what could possibly be (Derrida 1996)? How, for instance might a state funded “alternative capitalist institution” involved in elder care delivery be usefully connected with an alternative currency-based community? What might it mean if a group of cooperative enterprises in an area donated to a

community social fund, or created a coop credit union with the purpose of capitalizing more cooperative businesses?

The diverse economy/community economy is a different frame through which to imagine and enact alternative approaches to development. Two organizations in our area that we had known about for quite some time suddenly began to appear to us in different light when looked at from the perspective of the community economy. One was a local worker-owned copy shop, Collective Copies, and the other a community-based social justice organization located in Holyoke's Puerto Rican community—Nuestras Raices. We engaged in a “case study” of these organizations. In their evolution and various activities, they integrate the economies of generosity, volunteering, and the spaces of household and alternative enterprises in the course of their activities. They represent, in different ways, an alternative approach to development that draws an economy of generosity in relation to a (market based) economy of surplus.

Collective Copies

Towards the end of the REP we did a case study of area worker cooperatives. We elected to interview members of Collective Copies in Amherst, Massachusetts, partly because we had known some of the people in the cooperative for many years. Collective Copies was born out of a lockout in the late 1970s. Gnomon Copies—a capitalist firm—was unwilling to listen to worker demands for better wages and working conditions. Eventually, the workers at Gnomon were able to purchase the business because of the generosity of people in the Amherst community who supplied with them interest-free loans. In the twenty years since its formation, Collective Copies has been run as a worker-owned/worker-cooperative business. All decisions regarding wages, working

hours, and rotation of tasks are decided at weekly meetings (that cooperators are paid to attend). While 15 percent of their surplus (profits) is retained to expand the business, 75 percent is paid out to collective members in the form of patronage dividends. These patronage dividends—currently three to five thousand dollars a year—have facilitated a major goal for most of the cooperators, being able to own their own homes. This is a major accomplishment when one considers Collective Copies in relation to the economic fortunes of employees of capitalist copy shops. By collective decision, 10 percent of Collective Copies' annual surplus is directed every year to charitable causes—mostly local organizations in the Pioneer Valley. This could be imagined as a debt that is being repaid by current collective members. Alternatively, we could see this as a confirmation of Alperovitz's (2004) observation that worker coops are more committed to their local communities and are in a better position to be generous because they have lower return expectations than those that guide investors in capitalist firms. At the very least we see in this interaction between a market-oriented non-capitalist firm and the economy of generosity and volunteering, a commitment to an ethics of the community economy.

Nuestras Raices

Our intention in studying Nuestras Raices in Holyoke, Massachusetts, was to situate it within the Pioneer Valley's thriving alternative agriculture sector. In talking with various people involved with this community group, however, we realized that Nuestras Raices should be a case study in its own right. Nuestras Raices supplies us with a very rich example of development recast in relation to the community economy. Nuestras Raices began as a community gardening project in the early 1990s when the group was able to secure access to a single

plot of land owned by the Catholic Church. Nuestras Raices' garden project grew until they were presented with another opportunity to reclaim a vacant building located in the flats of Holyoke. This building was rehabbed, creating a green house, meeting place and business incubator, with the help of thousands of hours of volunteer labor and donations from a local architect and other area businesses. Nuestras' Centro Agricola currently houses both a restaurant and an artisan bakery which sells its organic breads to local specialty food stores and Community Supported Agriculture (CSAs) throughout the Pioneer Valley. Nuestras provides us with an example where gifts of material, labor, and expertise and the voluntary efforts of community members are the basis of a type of "primitive accumulation" for market-oriented businesses that, in turn, support the efforts of the parent organization. Neither the market nor the non-market oriented aspects of Nuestras are more important than the other to its social mandate as an organization. In Nuestras we came to see an approach to community economic development that integrates several aspects of the diverse economy in accordance with its ethical commitments to social justice and the empowerment of Holyoke's Puerto Rican community.

In both Collective Copies and Nuestras Raices, we see an economy of generosity—an outpouring of volunteer labor and gift giving—sustaining market and community-controlled businesses that in turn, through their activities, support the households and communities that sustain them. Nuestras Raices would not exist without the community of people that helped build the center and, at the

same time, this community would not exist without Nuestras Raices.⁴⁴ Nuestras Raices functions a community-economic space that sustains the community that created it—in this co-constitution we see the beginnings of a new approach to economic development.



Figure 3.5: Nuestras Raices as Node in the Community economy

When we presented the results of the Rethinking Economy Project to the Pioneer Valley community in stage 4 of the project, we used Nuestras Raices and Collective Copies as moments where an economy of generosity linked the volunteer and gift economies to the economies of alternative enterprises and household economies in the community. The articulation of these coordinates within community economy was ethical precisely because it involved engagement and experimentation within a space of possibility. This vision of development is very different from the one that guides conventional economic development. In the dominant development discourse the only decision is what kind of targeted incentive Holyoke would offer in the hope luring a new manufacturing base into its industrially zoned areas. There is, of course, no guarantee that any new jobs created will employ Holyoke residents. Nuestras Raices' approach does not abjure

⁴⁴ I mean this of course in a precise sense. The community of Nuestras Raices members

capitalism, but it does not imagine that capitalist economic activity is the only way to accrue wealth or transform communities.

From the perspective of this dissertation it becomes important to devise a methodological approach to research that situates health care in the diverse economy. If we imagined health care as a space composed of different places, practices, actors operating inside and outside of the market exchange in capitalist and non-capitalist social locations then its reform could become the object of a deliberative, ethically-driven politics.

Listening for Difference in Health Care: Methodology

It was around the time of the community conference (stage 4) in 2001 that I became increasingly convinced that there needed to be a case study of health care in the Pioneer Valley. I reasoned that health care was a huge part of the formal economy and, from having transcribed many of the interviews of our community researchers, I was beginning to sense that it played an important role in shaping the household economy. I began to wonder if this new approach to development, with its focus on the diverse/community economy, might lend fresh insight to the process of health care reform. What if we were to look more closely at people producing health care in informal or self-consciously alternative settings? What if it were possible, for instance, to examine the interaction between volunteering, gift giving, and state or non-profit health care providers? The diverse/community economy diagram has provided me with a template, focusing my research on particular organizations and efforts as well as giving me a means to establish potential connections between them. How might the examples of Nuestras Raíces

would not exist were it not for the organization's efforts.

and Collective Copies allow us to re-imagine the process of health care reform as one of developing and strengthening the non-capitalist elements of the health care sector? What if health care reform became a process of marshalling the resources of the community economy? This new way of framing the process would take us out of the context of a stalemated debate and its impoverished imagination of health care reform—the “choice” between cutting costs and optimizing delivery.

This idea has allowed me to read those interviews produced in the Rethinking Economy Project for instances of care. Forty-four out of seventy-two interviews contain at least some instance of caregiving. Likewise, the research that I have done first hand on the alternative, non-capitalist and informal care sectors has been guided by the desire to reframe the process of health care reform as one of building a powerful community economy that has health and well-being as one of its animating concerns. Like our community researchers, I have come to understand this process as one of documenting where care takes place, the relationships and antagonisms that are present in these spaces, as well as the ethics that animates and motivates these activities. Here is a partial example of what health care might look like once it is understood in relation to this heterogeneous representation of the economy (see figure 3.6).

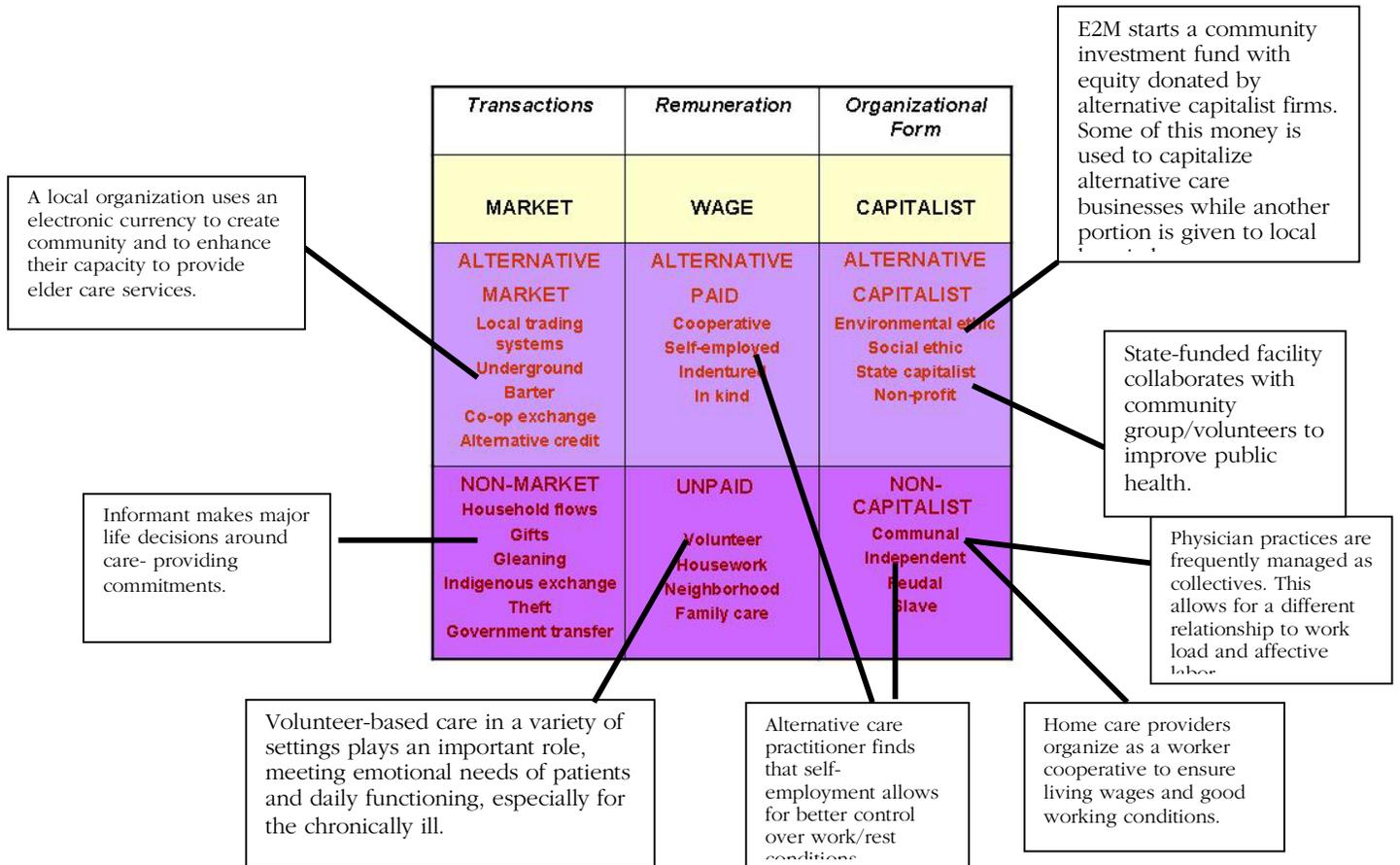


Figure 3.6: Filling in the Diverse Economy

Asking the Right Questions

The Interview Process

Both my involvement with the Rethinking Economy Project and my research on health care in the diverse economy has convinced me that the “community economy” comes into existence as different elements of the diverse economy are drawn into relation with one another. From this perspective, the goal of this dissertation is to understand the relationships and satisfactions that are at work in caregiving as well as the challenges and struggles, what we might think of as antagonisms, in the context of the places of the diverse/community economy. For instance, an auxiliary volunteer worker in a hospital may be providing palliative care services in a way that allows for paid hospital staff to

focus more effectively on other dimensions of the care process. In this instance we can see non-capitalist labor supporting and enabling a market-oriented economic activity. It is this interaction between informal and formal economy, between paid and unpaid labor, that constitutes the hospital/auxiliary as a site of a community economy.

Just as the diverse economy allows us to see different sites of caregiving, one is also led to consider the relationships at work in different segments of the caregiving economy. For instance, one independent alternative care practitioner pointed out to me that being self-employed allows her greater flexibility in terms of when and how much she works. Her existence as an independent allows her to pay better attention to the recuperative needs of her body that, as a massage therapist, relate directly to how well and for how long she will be able to keep up this demanding physical labor. At the same time, other aspects of this narrative can be seen in relation to other cells of the diagram. As a self-employed person she has greater flexibility in deciding whether and how much to charge for her services. Likewise, she also has bartered with artists, farmers, and other massage therapists—a practice that wouldn't be possible were she employed by a capitalist appropriator.

If we are going to pursue a politics of health care reform as a process of building a community economy, it might be important to understand particular antagonisms and struggles in different spaces of caregiving. Perhaps there are difficulties at work in household and other social settings where informal caregiving is being produced. Likewise, it would be imperative to document specific difficulties and challenges that are present in caregiving spaces that are operating in the context of the market. For instance, we could examine important

struggles over the appropriate staffing levels in hospitals and clinical settings where the quality and kind of care being provided is at stake. Alternatively, it might be important to ask someone volunteering at an adult day care center about the difficulties and dilemmas associated with providing care for Alzheimer's patients. Interviews with people involved with these caregiving practices allow us to see how they are (already) situated in the diverse economy. Getting at the motivations of these different caregiving actors, understanding the antagonisms and struggles that shape and define the spaces in which they work, provides us with the basis for an alternative imagination of health care reform.

I begin by asking the interviewee how they came to be a health care worker. As this narrative unfolds I ask additional questions which allow me to situate their caring labor in the diverse economy (e.g., are you compensated for the care you provide? Do you engage in barter exchange when caregiving?). Finally, I also give them a chance to speak of the satisfactions and frustrations they experience in relation to the work they do. Here we wish to learn not only what drives the person to give this care but, also, how the experience of care providing has transformed them. What hangs in the balance in relation to this question is conception of health care as an ethical space of becoming—a topic I will further develop in Chapter IV.

Transcription and Analysis.

The interviews generated by the Rethinking Economy Project were recorded and transcribed and then analyzed thematically with the help of NVIVO coding software. The interviews associated with this dissertation have been recorded and subjected to qualitative analysis in relation to the themes described in the preceding section. In the course of analyzing these interviews I devoted

considerable care to situating caregiving in relation to the diverse economy as well as the places, relationships, antagonisms and motivations associated with each interviews. I analyzed the responses of my interviewees in relation to one another in order to explore dominant themes that emerge. My hope is that by getting a different sense of health care as a space of problems and possibilities, and as a space of self-transformation, I might generate an alternative politics of health care reform.

Interviews

Interviewees were chosen to reflect as many elements of the diverse economy as possible. The REP interviews provided me with many instances of caregiving provided in the context of the household. Therefore it was important to make sure that I had interviews with people providing care in the context of the formal economic setting: individuals in charge of running non-profit or collective care enterprises, self-employed care providers, and volunteers operating in an institutional context. Interviews were conducted in person using a semi-structured questionnaire. Interviewees were given the liberty to focus on aspects of care production/delivery and encouraged to talk about what motivated them to be engaged in care providing, what challenges and satisfactions it afforded. A list of interviews can be found in table 3.1. False names were provided for interviewees who asked for them. I have collected basic demographic information about each interviewee as well what position they occupy in relation to caregiving and also the major thematic content that I have associated with each interview in the course of analysis.

Table 3.1: List of Interviewees

Interviewee	Role in diverse economy	Major Theme
REP interviews	Various, household, informal caregivers (ICGs)	Places and relationships, life decisions in relation to care
Ashley	ICG, Volunteer	Functioning, capacity, elder care in a community setting
“Stan”	Formal economy doctor, collective	Drive, communality, firm management
“Mike”	Formal economy, doctor, collective	General practitioner’s relation to small town community, trust and accountability
“Irma”	Formal, self-employed	Relationship between self employment and work vs. life balance
Tom Nolan	Formal, consultant	A national level policy consultant
Mike Savarese	ICG, family care	Difficulties and challenges associated with informal caregiving
Sandy Eaton	Formal, registered nurse, wage worker	Work place antagonism in the context of public hospitals
Kerry Olson	Formal, alternative medical practitioner, self-employed	Self-employment and professionalization, Alternative conceptions of health and health care
“Ruby”	Formal, self-employed, health aide	Self-employment and control over compensation
Anasuya Weil	ICG, family care	Relationship between self care and care for others
Robert Gallant	Highland Valley Elder Services director, Formal, institutional caregiving	Use of an electronic barter currency to produce a mutual aid network amongst elders in Westfield nursing homes
Jay Breines	Holyoke Health Center Formal, institutional	Collaboration between community groups and non-profit (largely state funded). Community oversight?
Lee Roscoe	ICG, family care	Difficulties with state agencies, hospital staff very helpful supportive.
Norman Haug	Physician, HMO board member, hospital	Engages in forms of alternative exchange,

	administrator, coroner	secured HUD grant to build critical access facility in his region
Cindy Jacques	Formal, elder care, nursing, ICG	Good perspective on elder care and also care as vocation?

CHAPTER IV
AFFECT, DUTY, ETHICS AND INFORMAL CAREGIVING: THE ROLE OF
COLLECTIVITY AND GENEROSITY

“Do not be mean with affect, for the fund itself is renewed in the spending.” Sigmund Freud.

Introduction

In chapter II we discussed the set of basic assumptions about the spaces and subjects (patients and providers) of care that govern health care reform discourse. These assumptions have us imagining that the self-interest of patients and providers manifests itself in the hospital and other clinical settings in a way that makes health care an enormous and ever-growing expense. Health care is said to be scarce because demand is assumed to exceed supply. This assumption is continuously restated in the dominant health care reform discourse, focusing the process of reform on constraining demand and containing costs. The fact that health care continues to be “scarce,” on the verge of crisis, that our approach to reform has been debated continuously in the same terms for nearly a century, is what tells us we are dealing with a social fantasy. This fantasy shares the repetitive qualities of all fantasy because the very effort to domesticate the symptom of “scarcity” simultaneously re-enforces its status as master signifier. As long the fantasy of reform is maintained, every study on regional and national disparities in health care delivery, spending, and outcomes only reinforces the centrality of the scarcity it attempts to domesticate.

Chapter III began by identifying a number of moments within that reveal inconsistencies in the basic assumptions that govern health care reform discourse.

We made use of these momentary inconsistencies to act as the analyst, to interrupt the continued elaboration of health care reform discourse and its contending fantasies. A particular reading of health care reform discourse allows us to see that patients are not simply consumers who will demand more care in the absence of constraints. Patients most in need of care—those facing their last year of life—may not always opt for the most invasive (and expensive) approaches to care if they are presented with a choice. While free market reformers may celebrate alternative medicine because it is paid for out of pocket by “empowered consumers,” we could also see that alternative medicine empowers the consumer in a different way—by enlisting them as partners in the production of their own well-being. Lastly, we saw that care produced in the formal market sector is only a portion of the total care produced in society. Informal caregivers, frequently unpaid, play an important role, particularly in relation to elder care. As I argued at the beginning of chapter III, while this important type of caregiving has received some attention in public policy and academic settings we are, admittedly, at a loss when it comes to imagining different ways that informal caregiving might be better supported by the rest of society.

While these insights about the different desires, relationships, and places of care are present in the mainstream of health care reform discourse, I would argue that they have the potential to dramatically reorient the way we imagine the process of health care reform, a possibility that is only limited by the dominant conception of economy at work in health care reform discourse. In the same way that the notions of the diverse/community economy enabled the CEC to produce an alternative approach to the process of economic development, these concepts

might, with equal facility, allow us to imagine a new approach to health care reform.

In the Rethinking Economy Project, the CEC used the notion of the diverse economy to rethink the process of economic development. One insight that emerged from this project was the way that community organizations and socially minded cooperative businesses can act as nodal points in the diverse economy. Businesses like Collective Copies and groups like Nuestras Raices concentrate generosity and volunteer labor as well as surplus wealth derived from participation in the market economy, in a way that expands their capacity to serve the interests of the community. In connecting the market and gift economy, paid and unpaid labor Nuestras Raices is involved in the construction of a community economy.⁴⁵

⁴⁵ As J.K. Gibson-Graham (2006) points out, the community economy is to be understood as a formally negative concept not a concrete positivity. Rather, it is the ultimately “amoral” diverse economy that functions for Gibson-Graham and the CEC as an empirical concrete positivity. Following Nancy (1991) they argue that while the fact of being-in-common functions as an ontology, it does not specify or fix the content of community. This distinction is important if for no other reason than the “positive” expressions of community at work in the public discourse frequently have a reactionary/nostalgic character. The goal of these expressions of common being seems to be to repress conflict in favor of a general—and frequently nationalistic—sense of belonging. For Nancy these evocations of common being carry with them the specter of totalitarianism since they are usually predicated on the exclusion of an offending or threatening other.

It was a particular form of common being that was evoked to defeat the Clinton health care plan in the mid-1990s. At that time the Republican mantra was to repeat a fragment of the Hippocratic Oath; “the first rule of health care is to do no harm.” The basic argument was that the mixed system of private insurance and government-funded Medicare/Medicaid was serving the majority of the population well enough and that any attempt at reform should preserve “what already works” for the majority. The insurance-industry-sponsored ads that I discussed in chapter II evokes a connection between common being and common sense in the portrayal of a typical white middle class couple—Harry and Louise. Interestingly enough this “common-being” sees the interfering state as the alien threat to the unified community of common sense. There was, of course, a hidden violence implicit in this evocation of a common being in relation to its excluded other—the tens of millions of people for whom neither employment based insurance nor Medicare or Medicaid was an option.

This argument against radical reformation of health care connects a common being to a fundamentally conservative impulse—things are fine the way they are for most of us. Such an imagination fixes everything in place—foreclosing on the task of theorizing how a different organization of care delivery, financing, etc., might fundamentally alter the boundaries between those who are cared for and those who are excluded from care. The politics of being-in-common would have us recognize that the inside/outside of a community is always in the process of being determined. In relation to health care, denying care or excluding people from access to care is a

As J.K. Gibson-Graham (2006) point out, the formation of a community economy is an ethical process that cannot be separated from a process of resubjection—the formation of a new sense of self, desires, and responsibilities. This new economic subject is released from the constraints of an economic imaginary fixated on accommodating or resisting the perceived demands of capitalist firms (CEC 2001a, J.K. Gibson-Graham 2003a, Byrne and Healy 2006).

In this chapter I intend to use these fundamental insights of the CEC to produce a new imagination of health care reform in relation to informal care providers. Situating health care in the context of the diverse economy allows us to re-imagine health care reform as a process of making connections across the divide between household and enterprise, formal and informal economies, market and non-market activity. The basic thrust of this effort is to shift the imagination of health care reform away from desperate attempts at domesticating scarcity into a register where reform is the process of producing both health and care by mobilizing and connecting the elements of the diverse economy. This shift in our understanding of the economic dimensions of health care and its reform is also intimately connected to the relational processes and emotional meaning of care delivery. From this perspective, while there are still limits to how much care can be produced, allocated, and consumed, these limits are newly understood as

moment of violence. It is difficult to see the denial of care as anything other than a form of structural violence as Paul Farmer (2004) has detailed time and time again in an international context. It is a cutting violence that closes off the cared for from the abandoned. Likewise, the struggle to expand coverage requires that we see the community as unfixed, expansive, and hospitable. There is, as Gibson-Graham (2006) and Özselçuk and Madra (2005) point out, a parallel between the negativity of being-in-common and the negativity that exists in relation to the distribution of surplus. There is always another way in which surplus wealth maybe distributed. Health care reform in this light can be seen as a continuous experiment in the allocation of surplus in times of scarcity *and* abundance.

socially, politically, and ethically constructed rather than being reflections of an intrinsic or natural scarcity.

In the rest of this chapter I focus on semi-structured interviews I have conducted with informal care providers. Subsequent chapters will detail what I have learned from care providers operating in the formal economy and in institutional settings. Most of my interviews in this dissertation focus on people engaged in the mundane aspects of health care—palliative care nursing, physicians in individual practices, health care clinic directors as well as informal caregivers, discussed in this chapter. I describe the nature and duration of their commitment while exploring the different ways that they have felt about the caregiving process, how it has affected and transformed them. Taken together they reveal a common ethical commitment to the process of caregiving as well as the circumstances that enable or undermine the caregiver’s capacity to remain ethically committed.⁴⁶

⁴⁶ It is difficult to surmount the criticism that, at best, I am making an argument here for a more generous attitude towards these facets of caregiving but that the process of reforming them would have little import in relation to areas where real “innovation and savings” might be achieved. What of biotech and pharmaceutical research or health information technology? Or further, a skeptic might argue we have yet to settle the question of how health care is to be financed and that this matter is pressing since the baby boom generation is likely to press our ability to deliver care to the limit over the next few decades. My response to these challenges is that these other elements of health care also exist in relation to the diverse economy and, by means of imaginative connection, *could* be made part of the community economy of health in a way that assures fidelity to an ethics of care. In this regard I believe that the diverse/community economy has much in common with non-representational theory—its value is not to be found in the “know and tell” approach to knowledge, though it is a powerful descriptive tool. Rather, as Thrift (2004, 82) suggests in relation to his work on non-representational theory, it is a question generator. Recognizing, for instance, the true potential of health information technology in patient record keeping will only be realized if the information is portable from one physician’s practice or hospital to the next. Given that it is unlikely that many companies producing competing software packages will produce the maximum portability of patient information, what (from the diverse/community economy) perspective *would* be likely to do so? At a minimum it would require the *cooperative* adoption of an industry standard. This to me suggests other possibilities—what if the software was not developed (only) commercially but was instead an open-source effort?

Subjects of Care: From Affect to Ethics

All of my interviewees, those that worked in the formal care economy as well as those outside it, seemed to share common beliefs about what it means to be a caregiver, what effective care is, and what is required to reform health care. I have come to think of these commonalities as traits that define the caring subject. The experiences, values, and practices these subjects share in common suggest a connection to the diverse/community economy—one that might allow us to re-imagine health care reform if they were properly articulated. The first commonality is that all of my interviews spoke of the affective intensity of being a caregiver. The caregiving experience transformed and continues to transform them in a variety of ways—redefining what it means to be empathetic, what behaviors one can tolerate from others (the patient), even how one understands and confronts social taboos and conventions. Second, while they all said their commitment to caregiving was directed by a notion of personal duty or ethics, they also recognized how their effectiveness depended upon receiving support from the greater community. If the affective intensity of caregiving is what propels unflinching ethical commitment, then it is these supportive circumstances that allow caregivers to remain faithful to this commitment. Lastly, almost all of them saw what was variously called “greed,” “capitalism,” the profit motive or “money medicine” as a force that undermines their ability to care effectively.⁴⁷ This might be understood as an anti-capitalist political stance—and, in part, it is. However, it can be theorized also, from the perspective of the diverse/community economy, as

⁴⁷ Or perhaps, to put it into a form closer to what was actually said, these sorts of “economic” concerns got in the way of being affected by and affective in the context of the caring encounter.

a call for aid, the expression of a desire to build the type of community economy that enables fidelity to the ethic of care.

It is only in reflecting on the interviews that this connection between the affective intensity of care, ethics, and the relation of affect and ethics to the economy began to emerge as a consistent theme. In some sense the concern with affect among the interviewees was unsurprising—caregiving is a type of emotional labor. However, interviewees spoke of affect in a way that seemed to resonate with contemporary psychoanalytic work of Žižek, Badiou, and others currently involved retheorizing the relationship between economy and subjectivity (Byrne and Healy, 2006; Gibson-Graham 2006; Özselçuk and Madra 2005). It strikes me that affect is an appropriate starting place for considering what interviewees had to say about caring labor.

Towards a Definition of Affective Labor

Caregiving is a form of affective labor, and it is easy to imagine that part of what a caregiver does is give comfort to the patient, keeping their spirits up, managing their fears, crying with them or even just reassuring them with touch (Folbre 2001). Both Folbre and Fraad, Resnick, and Wolff (1994) point out that many occupations involve some type of affective labor. In different ways these theorists demonstrate that the capacity of people to provide affective labor can be severely strained both in the context of the household as well as in certain commercial activities. For Folbre, the commodification of caring labor—child minding, elder care, meal preparation—inherently carries the risk of alienation. In contrast Fraad, Resnick, and Wolff argue that caring labor, like any other productive economic activity, can be thought of in relation to the Marxian notion of class. Commodified caring labor can be performed in the context of an

exploitative class relation. “Productivity gains” in the capitalist airline industry might rely on asking fewer flight attendants to provide the same emotional labor for more people, effectively increasing the rate of exploitation.⁴⁸

Work that goes on in households can also be theorized in class terms. The “traditional” household positions the male head of household as the first receiver of the surplus produced by his wife (and others). This exploitative relationship is usually cemented through notions of reciprocity in which the man is supposed to support and protect the members of his household in exchange for their labor. The feudal household class process has been subject to severe strain in the United States since the 1970s which in turn has led to the formation of households in which independent (self-provisioning) and communal class processes predominate. From a Marxian class perspective, the alienation of commercial caring labor is not the result of the commodity form itself—the performance of affective labor for exchange—but is instead an outcome of exploitative appropriation, whether that class process takes place inside or outside of the context of production for exchange. This means that caregiving could be produced in an exploitative class relation whether it is produced in a hospital or a home.

⁴⁸ Van der Veen (2001, 2002) applies this same logic to prostitution located largely in the informal sector. For Van der Veen it is important to bear in mind that class overdetermines the meaning of sex work. A sex worker in a slave class process has far less control over the amount or intensity of work, affective or otherwise, that it is necessary to perform to reproduce herself than a sex worker who is self-employed. Van der Veen’s work is challenging in this regard, especially for feminists theorists who wish to regard all sex work as inherently degraded or exploitative. What’s remarkable is that the differences that the class perspective can introduce into the discussion over sex work allow for a much greater variety of forms of political engagement. The class-based politics in relation to sex work might mean one thing for yoghinis in India and quite another for workers seeking to unionize their commercial peep show venue. Van der Veen might argue that these differences are important even if one retains as an overall goal the complete separation of sex from work.

The concept of exploitation in the affective labors is a crucially important point because it allows us to understand why there are intense struggles going on in fields like nursing over working conditions and staffing levels. There is, however, another point that can be made about affective labor: the caregiver is also affected by the work that they do.⁴⁹ Paying attention to the affectivity of caregiving does not so much direct our attention away from the concerns of class analysis but ultimately allows us to deepen our understanding of the difference between exploitation vs. non-exploitation. Massumi (1996), writing in a Spinozist vein, argues that the reception of an affective intensity—from a piece of music, or of art, or through a momentary exchange between people—is an experience (temporally) separate from and yet constitutive of its emotional meaning.⁵⁰ This means that providing caring labor for a family member has an affective intensity that can have different emotional meanings for the caregiver. The emotional significance of affect can change over time or be different for different people. It is even possible, according to Massumi, to have multiple emotional reactions to

⁴⁹ Dorothy McCade (2005), at a recent organizing event held by the Mass Nursing Association, pointed out that one out of three new nurses will leave the field of nursing by age thirty and that the principal reason for their departure is “caregiver” burnout.

⁵⁰ Massumi relates the story of a group of German cognitive scientists who heard about complaints from a number of parents about a spot airing on German television that depicted the relationship between a boy and a snowman that he had made. The short, shown without sound, depicted a boy who made a snow man and then, realizing that the snow was melting, moved him to the forested mountains so that he might escape the sun. The short ends with the snow man staring sadly at the boy and the boy at the snow man before turning and departing. Doves of parents called the station and complained that this story was too sad to be shown to children. The intrigued scientists began showing different versions of the film to German children—one with a narrative voice over, one with a musical score that emphasized the emotional content of the short, and lastly in the original version. Massumi tells us that the children were then asked to rate which version of the story they liked the best. It was found that the children were pleased most by the “saddest” version of the story and reported that it made them feel happy. The implication is the reception of intensities was read in relation to a different emotion by the children. Could it be that these children were able to receive this intensity and be positively affected by it, while it was the parents who were emotionally traumatized by it? Perhaps, sadness and happiness, trauma and elation are not as separate from one another as our emotional experiences would initially suggest.

the same affective experience. The importance of this distinction between emotion and affect—their separation in time and relative autonomy with respect to one another—allows us to see their relationship as contingent rather than fixed.

This Spinozist conception of affect in relation to caring labor has important implications for how we can (re)conceive of health care and its reform. How caregiving affects the provider has not been properly considered in relation to health care and health care reform. To be sure, there is an enormous literature that teaches physicians, nurses, and other health care professionals how to cope with the emotional consequences of work. While acknowledging this literature, the famous physician Patch Adams (1998) poses a daring question: how can we reform health care practice so that it is a source of joy rather than something that is assumed to inevitably dampen the spirit? Perhaps before we can supply an answer to Dr. Adams' question we need to trace, however tenuously, the link between the affect and the work of caring.

The Importance of Being Affected

Dr. Francis Peabody, writing in 1927, observed that medical training focused increasingly upon the technical aspects of caregiving and the treatment of disease while paying little attention to cultivating the emotional intelligence that is required to “bond” with the patient. He argued that while

the treatment of a disease may be entirely impersonal; the care of the patient must be completely personal. The significance of the intimate personal relationship between physician and patient cannot be too strongly emphasized, for in an extraordinarily large number of cases both the diagnosis and treatment of illness are directly dependent upon it. (Peabody 1927, 877)

Peabody also noted that separating physical disease and pain from psychosomatic malady is a skill that is predicated upon the physician's ability to observe and

interact with the patient. He spoke of the clinical need for physicians to be able to listen to and empathize with patients, in short, to be affected by their presence in the course of treating an illness. At a time when modern medical practice was still in its infancy, Peabody was already voicing concerns that mastering the “technical” aspects of treatment was threatening to displace the time required for the physician to acquire empathetic capacity. Peabody suggested that medical schools devote at least some time to this aspect of professional practice but he also recognized that this is necessarily a skill physicians acquire on the job. The capacity for empathy and discernment is something conferred by performing the labor itself and being affected by it.⁵¹

As we saw in chapter II, Dranove (2000) argues that affective labor/care was (and is) what physicians offer when they cannot cure. He asks us to consider a hypothetical instance in which we are ill and presented a choice between an average physician with exceptional bedside manner and an impersonal physician whose knowledge and expertise is in the precise ailment that we have. According to Dranove, the choice is obvious. He goes on to argue that patients unduly value the “caring-ness” of their care providers and that they should, instead, evaluate physicians, courses of treatment and hospitals in relation to another measure, for instance, quality of outcomes or medical error rates.

One implication of Dranove’s argument is that “affective” labor, while nice, is also largely irrelevant to medical outcomes and that emphasizing it is a waste of money. While Dranove is quite right to insist that there are differences in levels of

⁵¹ While work presents the physician with the opportunity to hone their emotional intelligence not every physician chooses to do so. Nor does every physician recognize the importance of emotional sensitivity. While medical school cannot, ultimately teach something that is acquired on the job, perhaps there are ways of teaching physicians to how to learn on the job.

expertise of physicians and in the quality of medical facilities, does it follow that it is unreasonable for patients to be concerned with the quality of the emotional labor they receive from their providers? The obvious rejoinder to Dranove's argument is to ask why one cannot have physician who is both technically proficient in the delivery of care and affectively competent. Why shouldn't affective labor be considered among the criteria of excellence in health care and as part of what people deserve as patients?⁵²

Jerome Groopman's fascinating *Anatomy of Hope* (2004) can be read as a rebuttal to Dranove's argument that the "bedside manner" of the physician is of little or no consequence. Groopman describes the critical role that affect plays in the treatment of deadly disease. The affective encounter between patient and physician and its emotional consequences for both parties can create the conditions for healing (hope) or undermine it utterly (despair). Groopman argues that the technical treatment of disease may be more tied to its affective dimensions than we had previously realized. He has been a practicing oncologist since the 1970s and has participated in technological advances in the treatment of cancer. Over the course of his career, he has witnessed particular types of cancer go from being incurable to treatable and even curable. Alongside these technological advances he has noted over the years how the attitude of the individual patient plays a tremendous role in their survival—specifically their ability to be hopeful

⁵² It is here that we see another element of Dranove's fantasy of reform. Competition on the basis of "objective" data could make health care more efficient and effective *if only* the public were less invested in the bedside manner of their doctors. The wish that is being imaginatively fulfilled/frustrated is a wish for rational consumer subjects freed from sentimentality. It is precisely because of the role that "affective competence" is playing in Dranove's fantasy of reform that it cannot be seen as a criterion for quality care.

about the course of treatment. In turn he also realized that his attitude as a physician played a role in whether or not the patient was hopeful or despairing.

Groopman came to this understanding through the course of his clinical practice. No one taught him how to deal with the reactions of patients to receiving a cancer diagnosis and the role that attitude played in the course of treating disease. He learned early on, for instance, that it was folly to be dishonest with the patients—either to spare them grief or in the hopes of keeping them encouraged. A Pollyanna attitude is inevitably disappointed in the course of treating cancer. “Unexpected” relapses can crush the patient’s resolve to continue with treatment. Later Groopman learned that it was folly to be “completely honest” with the patient about their prognosis in that it severed the patient from any sense of hope and also any chance of the patient relating to him as a human being.

For Groopman hope is not unwarranted optimism. Nor, for Groopman, is hope what we have when empirical investigation suggests a favorable outcome. Hope is the recognition of the singular and contingent circumstances of an individual patient’s life in relation to the variable progression of any disease. At the same time, hope is something that is a birth right that humans should enjoy regardless of circumstance. As one of his fellow oncologists explained as he suffered from a cancer that he himself would have considered incurable, “I have a right to hope.”⁵³

⁵³ This oncologist was a specialist in the very form of stomach cancer that he developed. The cancer had metastasized and spread to his liver and other parts of his body. This oncologist knew very well that his own assessment of a cancer this advanced would be that the patient was terminal. However, he refused to give up hope, subjecting himself to the most rigorous and painful chemotherapy regimen, despite the odds against him. It wasn’t until fifteen years later that he told Groopman that it was his right to hope.

According to Groopman, this understanding of hope as a subtle sense of contingency and possibility has different meanings to different patients. Consequently, cultivating hope in a patient is always going to mean something different in each particular case. Groopman describes his experiences with one patient, Dan Conrad, who had a particularly aggressive form of non-Hodgkin's lymphoma. The tumor was operable and yet the patient refused treatment, simply repeating that he knew there was no hope for him. Groopman, recognizing that Dan was a Vietnam veteran, used the metaphor of war hoping that it would inspire courage. He asked him to think of his cancer treatment as the site of a winnable battle in which he was the general and the physicians were soldiers awaiting orders. When this failed to elicit consent, Groopman asked Dan to think of his wife and family. In response to these entreaties Dan simply responded that he knew with an absolute certainty that he was going to die.

After talking with Dan for few days Groopman, finally—and quite accidentally—learned the origins of his depressive sense of certainty. Dan's wife had spoken with a friend of her husband's from the army and she relayed this information to a colleague of Groopman's, who in turn relayed it to him.

'Then the army buddy said to Mrs. Conrad that Dan's situation was just like the case of another veteran from the unit,' Virginia related. Not long after the war, Betsy learned, one of Dan's closest friends had developed cancer. The caller did not say what kind of cancer, but Dan had kept a vigil at the bedside from the time his friend went into the hospital, through the multiple complications of his ICU stay, until the man died. (Groopman 2004, 103)

It was then that Groopman realized that his military analogy had completely "backfired." He saw that he had failed to

understand Dan as a person, to probe deeply into the details of his life. It seemed easy to integrate his status as a veteran into the typical battle scenarios that I and other doctors painted for patients.

But instead of picturing himself as a victorious warrior, he must have seen himself as so much cannon fodder, like his friend. (Groopman 2004, 103)

With this knowledge Groopman was able, finally, to appeal to Dan's sense of reason. He argued that cancer treatment had advanced considerably in the intervening years and that his friend's fate was not necessarily his. It was enough of an opening to allow Dan to see the reason behind consenting to treatment. According to Groopman, once the mass of the tumor had been reduced enough to relieve the pressure on Dan's lungs, his body was no longer able to convince Dan that he was on the threshold of death.⁵⁴

The point not to be missed here is that this expensive, technical, and ultimately life- saving operation would not have occurred if Groopman lacked the time, skill, or inclination to understand the source of this man's resistance to treatment, the specific origins of his sense of hopelessness. Receptivity to affect is what allowed Groopman to be effective, to think of the treatment of illness not simply as a technical process but one where affective intensities, and the bodily sense of hope or despair they produce, must be mediated as well.⁵⁵

⁵⁴ As Groopman points out, Dan's body was not wrong:

Dan's sense that he would die was articulated in vague and visceral terms. From seeing cases like his and that of the woman with aortic aneurysm who felt impending doom, I have come to believe that the way the body talks to the brain powerfully shapes our sense of hope and despair. Dan's feeling of growing suffocation, the increasing pressure on his esophagus and bowel, the compression of blood flow in the aorta and vena cava, I suspect, were all subconsciously perceived by the brain and translated as prefiguring death. The cerebral processing of that visceral input as a signal of death was accurate. (Groopman, 2004 120-121)

Of course, neither the brain nor the body knew of the possibilities that new therapies could bring to Dan. According to Groopman, Dan was able to switch from a feeling of impending doom to one of hope and possibility because the course of treatment affected his body in a way that it no longer prefigured death.

⁵⁵ While Groopman was able to get Dan to assent to an initial dose of chemotherapy to save his life immediately, getting Dan to see hope in the extended process of chemotherapy required another approach that was adopted by one of Groopman's colleagues, Deirdre Dolan. She placed Dan,

If opening himself to the emotional meaning of disease is what allowed Groopman to save the veteran, in other instances this same capacity is what allows him to respect the wishes of another patient to stop treatment. Groopman relates the story of a Barbara, a woman who developed breast cancer for the second time after a short period of remission. This woman was absolutely clear with him that she wanted to continue treatment only so long as it enabled her to continue to enjoy life and that she would be the person who would make that determination. During her initial consultation Barbara handed Dr. Groopman a card authorizing her pastor to be her legal health proxy and with that gesture communicated that she had an understanding that this care was to be palliative in nature. Groopman was suspicious of her equanimity in the face of death but also was curious as to its origin, if indeed it was her genuine emotional response to terminal illness.

Groopman learned that Barbara was a deeply religious woman and she probed him about his own beliefs during the course of her visits. There was something in her curiosity and courage that deeply affected him. After sending Barbara's cancer into a series of temporary remissions with first, second, and third line chemotherapy regimens, Groopman realized that no other treatments were left to keep Barbara's cancer in check. When he told her that he could do nothing more for her Barbara's composure faltered for only a moment and then she responded that he had one medicine left to administer—the friendship that they had developed over the course of the past year.

After Barbara left, I sat in my office. My eyes moved to a book on the shelf that I had read not long before: *Doctoring* by Eric Cassell.

deliberately, next to an older woman, Doty, who was successfully approaching the end of a course of the same chemotherapy that Dan was in for. Dan and the woman formed a bond. It was this bond of identification that allowed Dan to reason that if Doty could make it through chemotherapy then so could he.

Cassell, a primary care physician, wrote it at the end of a long career. He articulated a feeling that I had vaguely sensed but never fully realized. There are some patients whom a doctor grows to love. It is a unique type of love, distinct from any other type of love the doctor has experienced before. It moves outside of the bounds of the usual doctor-patient relationship; feelings and thoughts that are no longer strictly professional and are shared among true friends. Barbara had sparked that love in me. (Groopman 2004, 132)

Clearly Groopman's capacity to listen and be effective as a physician was what allowed him to put Barbara in control of her own palliative treatment. Groopman was affected by Barbara in a way that allowed him to deepen his appreciation for the meaning(s) of hope. While Groopman agrees with Kubler Ross that acceptance is the final stage of the dying process, even "acceptance" is not without hope. Barbara persisted to the end in her relations with Dr. Groopman, her church and even in mediating conflicts in her family. Her hope was that the connections she made with people would persist after she was gone. If Groopman's experience with Dan illustrates the importance of understanding what prevents a patient from having hope, his experience with Barbara illustrates how hope can persist even in the face of certain death.

Through Groopman's analysis of hope, we can see how care is productive of affect and that caring is a process of negotiating one's way through the affective intensity. According to Groopman, getting the patient to recognize the singular and contingent outcome of illness or injury is what is required to give them a sense of realistic hope. Imparting hope requires an attunement to the particular life history of the patient and also a receptivity to their desires and anxieties. It demands, ideally, a certain opening up on the part of the caregiver, even an identification with the patient. This is, to be sure, a demanding practice. In my view this is precisely why many care providers speak of the need to establish a

certain “distance” or of a need to maintain a certain emotional reserve outside of the context of caregiving. Perhaps we can understand this need for distance not as a calculated callousness, but rather an attempt to achieve the correct point of tension, a way of negotiating between identifying with patient while bearing in mind their autonomy as well as one’s own psychic and physical integrity. Cultivating hope, allowing it to come into existence in a particular way for each patient, is a skill that Groopman has acquired by being a physician. It is something that has deeply affected and transformed him.⁵⁶

I would argue that this experience of becoming a caregiver is not confined to professional providers. To return to Arno *et al.* (1999) and Donelan (2002), both of these researchers painted a decidedly split representation of the emotional impact of informal caregiving. On the one hand caregiving was draining physically and financially, depressing and physically hazardous. On the other hand, their informants also spoke of it as one of the most important and rewarding aspects of their lives. The in-depth interviews I have conducted with informal care providers all attest to this split—care is exhausting and yet simultaneously the labor itself is a source of energy, drive and satisfaction. Are we not confronted here with an instance where the emotional and even physical impact of caring labor is autonomous from its affective intensity? This dichotomous experience of

⁵⁶ The second half of Groopman’s book details his experiences as the patient of a doctor who was treating him for chronic back pain. It was really this personal experience that taught him the connection between hope—a sense of possibility—and the neurophysiological condition of his body. This physician, after examining Groopman, had determined that nothing of the initial injury that caused Groopman’s chronic pain remained and that a combination of Groopman’s continued belief in his pain and the carefulness with which he treated his body had progressively weakened his back. The goal should therefore be to get Groopman to re-invest in the strength and capacity of his back by gradually relearning how to use it. Groopman wrote that this course of treatment was hard and painful but that eventually, once his back was strengthened, it also “learned” that it was no longer injured. Here again the connection between body and emotional meaning seem to be connected in a reciprocally affective relationship.

caring labor was repeated by professionals I spoke to in the field—from administrators, to surgeons, to alternative practitioners. Recognizing this split nature of caring labor as enabling/disabling, depressing/fulfilling seems to suggest that the goal of health care reform should be to maximize the enabling affect of care while minimizing its draining, depressing side.

It is perhaps impossible, in the final analysis, to fully eliminate the “draining” aspects of care or to create only those circumstances of caring that maximize joyful participation. I believe that taking the affective intensity of care seriously has implications for how we might imagine health care reform. Health care reform might begin with listening to or even reinvigorating an already existing discourse on how to negotiating the affective intensity and emotional consequences of caregiving. This will perhaps allow us to imagine a process of health care reform that goes beyond the steady application of a miserly attitude and towards one that is directed by a different ethic.

Ethics, Duty, Care, Symbolic Death and the Affective Event

In the section that follows draws upon emergent theorizations of an ethic of care. Beyond being the simple expression of a “human desire” to care for others—for instance, Carol Gilligan’s (1982) imagination of a feminine ethics of care—I am going to argue for an ethic of care that involves itself with a process of clarifying duty in intensely affecting circumstances. Here the principal issue is not whether to care, or why one cares, but rather how. Answering this question of “how to care” frequently brings the care provider face to face with the contradictory and intensely affective experience of being a care provider. While this may involve a sense of felt obligation, caring sometimes demands the transgression of social norms that separate self from other. At first blush, it is

difficult to imagine that “duty” towards others and “transgression” of others are anything other than opposed to one another. The new Lacanians, however, make the case that the fulfillment of duty requires this deliberate transgression—that caring, like love, violates the law that separates self and other. From this perspective, this transgression either undermines or transforms the person who bears this duty-to-care. It is this understanding of duty that makes the recent work of psychoanalytic theorists relevant to a new conception of health care reform. These theorists point out that fidelity to an ethics of care is actually a commitment to being “unmade” or even potentially undone by the caregiving process—receiving its affective intensity, risking literal and symbolic death, in a way that transforms the caregiving subject.

Ethics and Duty

I would argue that Groopman’s treatment of the two cancer patients Dan and Barbara reflects what Freedman (1999) describes as the difficult, everyday ethical dilemmas facing the practitioner. Freedman argues, from a Jewish ethical perspective, that medical ethics should concern itself with both duties and rights. Duties are defined as our social obligations to others while rights govern who is in a position to make decisions in relation to a particular situation. According to Freedman, secular medical ethics in the West has generally concerned itself with the rights of the patient, the family, and the physician to make decisions in relation to the caregiving process.

In the western legal tradition, the right of the patient to make decisions about their own care is considered sovereign as long as they are competent. Their

right to decide for themselves trumps those of every other party.⁵⁷ When a patient is not a competent decision maker this same rights-based discourse assumes that the family has both the best interest of the patient in mind and a prior knowledge of what the patient might wish for. Freedman argues that these are relatively weak arguments for families having the right to make decisions for incompetent patients. For Freedman it is not that families are bad proxy decision makers but rather that the language of “rights,” their right to make decisions on the patient’s behalf, fundamentally misconstrues the ethical dilemmas that attend caregiving.

For Freedman, the trouble with an exclusively “rights” focused discourse in relation to care is that it inevitably focuses our attention on whether or not family members or other health care proxies deserve to occupy that position. Freedman argues that, from this perspective, it is as if the family is both the only health care proxy and, simultaneously, the worst health care proxy. As a consequence, our attention is focused on discerning their intentions as caregivers, why they care. The case of Terry Schiavo, who in March of 2005 was finally allowed to die after a decade of legal wrangling between her parents and her husband, dramatically illustrates this point. It was as if Terry’s seemingly animate body became a screen upon which the husband and parents projected what they imagined to be Terry’s wishes regarding her care. In turn the contending proxy parties became the objects of social-fantasies as the Schiavo case became a central concern of the public, first in Florida and then on a national level this past year.⁵⁸ This popular

⁵⁷ Using Groopman’s encounter with Dan as an example, we can see that Dan had a right to refuse treatment. For Groopman this was not the “end of the matter” but the beginning of *his* ethical dilemma as a care provider.

⁵⁸ Freedman also wrote about a number of experiments in which family members and spouses were separately asked questions regarding extreme medical interventions and extraordinary efforts

discourse was similarly directed by a desire to divine the actual motivations of the parties involved, which rapidly devolved into imagining the worst in relation to each party. The husband was imagined as either the person who heard the last wishes of his wife and only desired to carry them out or as a crass and uncaring man who simply wanted to be rid of her. The parents were imagined as either people who had an intense and undying love of their daughter or as religious zealots whose desire to care for their daughter reflects some intense need to dominate or infantilize her. The law, and eventually Congress, became involved in determining which of these two parties really “expressed” Schaivo’s interests and which party was directed by pathological self-interest.⁵⁹

at life extension. It was noted that most people imagined that the wishes of their spouse or family member reflected their own, though this ultimately proved a very poor indicator of the other’s wish.

⁵⁹ One of Lacan’s famous diagrams that describe the formation of the subject is schema L (Leupin 2004). Žižek summarizes the meaning of the L schema by saying that our self-conception (unless we are psychotic) is derived from a redoubling of reflection. It is not simply that my existence is confirmed by the other’s recognition as Levinas would have it (the self’s dependence upon the other). There is a second layer: I imagine myself as I imagine you seeing me. Thus the “ego” self-conception is a projection about ourselves that we imagine is confirmed in the other. The sense of self derived in schema L is dependant upon two imaginary lines of identification that, as it were, covers their own tracks. It is the second imaginary line in “I imagine the way you imagine me” that ultimately obscures the origin of self-conception as projection.

What is the applicability of the schema L to the Schaivo situation? On the one hand we clearly have the two parties seeing their own wishes incarnated in Terry’s body—the husband’s wish for his wife to be released from living death, and the parent’s wish to see signs of life in involuntary movement of their daughter’s corpse. In turn Terry’s husband and parents become screens that ultimately confirm and validate the public’s sense of self. This “confirmation” could take a number of forms:

- Terry’s husband is an enlightened realist that reflects/confirms my own reasonableness about death and letting go.
- Terry’s husband is a calculating monster who places his own desire before duty—I would never do that!
- Terry’s parents are dutiful protectors and I would do the same, no matter what the cost.
- Terry’s parents are monstrous narcissists who seek to control their child, even in living death!

Is it possible that these different projections add an additional layer of complexity to schema L in which the subject of the social fantasy both identifies with one party and reviles the other? Fantasies are forms of compromised enjoyment in psychoanalytic theory. Perhaps the true locus of the monstrous is in this social process of identification/disidentification, in which the actual parties involved are merely instruments of the public’s enjoyment.

What if the actual lesson to be learned from the Schiavo case is that the “rights” based approach to an ethics of care focuses our attention on only one dimension of the relationship between caregiver and patient? What if the tragedy of the case was that no one, apparently, was in a position to really intervene in the relationship between Terry’s parents and her husband in a way that would clarify the best course of action to all concerned? While rights are an important aspect of ethical decision making, according to Freedman, it is an insufficient basis for an ethic of care—the role of duty needs to be considered even (and perhaps especially) when it is clear who is empowered to make the decision. Without denying that there are cases where conflicts of interest do present themselves in relation to caring for the patient, for Freedman a rights based discourse fails to capture or resolve the ethical dilemmas that surround caregiving.

Families claim the right to make these decisions. Within our legal system, a claimant that seeks the court’s attention must come armed with a right. In our courts, families must speak the language of rights. But in considering the role, and claim, of families to decide, we should not allow the moral point of view to be co-opted by the legal point of view. Very few of these cases will end up in court; even serious conflicts will usually be resolved within the clinical setting, and it is that setting that must remain our chief concern. “Families claim the right”: Is that an accurate understanding of the role that families claim, or is it rather a clumsy, legalistic misconstrual of the moral basis of the claim of families to decide about the care of their incompetent members? The best and most natural way of describing the claim of families speaks instead the language of duty: Families understand that it is their obligation to see to, and decide about, this patient’s medical care, as it is their obligation to feed, clothe, comfort, and succor. This duty of medical decision making is continuous with all the other obligations owed to a family member who is unable to care for herself. (Freedman 2000, 98)

Freedman argues that an ethics of duty and those of right are complementary. After all, the legal right for a family to care for their own members stems from the fact that they ought to and they are able to do so (Freedman 2000,

100). Once the problem of caring for the patient is reframed in relation to a notion of duty the problem often enough, according to Freedman, is not one of conflicting interests but rather the genuine ethical quandary of what is the right thing to do for the patient. Adult children of parents in need of care often face a choice between submitting a parent to a course of treatment that might be painful or degrading or facing the consequences of not pursuing treatment. In this way decisions made upon behalf of incompetent patients tend to be experienced by the caregiver as a disconcerting imposition of their will upon the patient, a transgression that brings them into startling proximity with the patient in their infirmity.

Paying attention to the duties as well as the rights of proxy caregivers, understanding their complementarity, also allows us to appreciate how they might be the locus of a contradictory or split affective intensity. Duty captures the sense of onerousness that may come with a familial obligation to care as well as the sense of satisfaction that accompanies its fulfillment. In this way duty, like the notion of (conflicting) legal rights, describes a kind of agonistic space in which our relationship towards the other (the patient) is being continuously worked out. The role of ethics in relation to duty appears in Freedman's work as a process of being a guide, a way of working through the contradictory affect of caregiving in a way that ends with successfully discharging one's duty. Ethics here is figured as a process of interrogation and reflection whose aim is to clarify the correct course of action for the caregiver.

Freedman's method as an ethicist employs Talmudic law to help both his fellow physicians and proxy health caregivers through difficult ethical dilemmas and feelings that accompany the caregiving process. As he puts it, Jewish cultural

law pays particular attention to relationships of obligation between individuals and so provides a language that allows people to clarify the meaning of their duty in each individual instance. The Talmud is arranged so that one sees how successive generations of rabbis understand and resolve particular ethical dilemmas. The Talmud offers a way of posing and then resolving questions of duty in a way that dispels tension. Freedman begins his book by giving the example of a primary care provider treating an elderly patient who had been in his care for more than twenty years. The woman expressed a wish to die a natural death. In consulting with Freedman it became clear that this doctor was terribly distressed by her wishes.

He feels a terrible ambivalence about agreeing to her wish to withdraw treatment, and anguish is evident on his face as he asks “Is this my decision to make or hers? Isn’t she asking me to exercise more power than any human being should have?” (Freedman 2000, 33)

Freedman recognized that what tormented this physician was that a patient he had known and treated for twenty years was asking him to play God, to determine the time of her death. The wish of the other/patient was for the physician to bear an impossible duty, an unbearable burden. He told this physician to ask the patient a series of questions where she was able to articulate a definite preference—for instance, the wish to not be resuscitated in the event of heart failure. Freedman’s intervention was to reframe things in such a way that the patient was able to articulate a definite set of wishes so that the physician might be relieved of having to make a decision that he felt was beyond what he should be empowered to decide. Freedman’s intervention allowed the doctor consulting him to fulfill his sense of duty by restoring a proper sense of proportion to the relationship—between patient and physician rather than patient and God.

Ethics and Transgression

For Freedman ethical behavior is discerning one's duty. This must not be confused with simply identifying (with) and fulfilling the wishes of the patient. Likewise, ethical behavior is not living according to a prescribed morality that directs one's behavior. Rather, the ethical subject is committed to her duties in relation to a specific context. On occasion living ethically requires the transgression of social norms, what Copjec (1995) refers to as the temporary suspension of the law in the course of the ethical act.⁶⁰ One of my informants who I named Dr. Stan spoke briefly about what is sometimes required to get the patient to comply with cardiac intervention. The patient will resist a needed intervention because they are afraid, because they don't trust you, or because they imagine they might receive better care somewhere else. Once these anxieties, mistrust, or unreasonable expectations have been discerned, according to Stan, it is the duty of the physician to somehow persuade the patient to do what is necessary to maximize their chances for survival:

Stephen: What does that entail?

Dr. Stan Ah,...lying, con, a con artist. A good doctor is a good secretary, a good con artist, a good policeman, priest, a lot of things...

⁶⁰ This notion of an ethics of care as transgression allows us to further specify the meaning of the "common bond" we discussed at the outset of this section. It is not merely a sense of attachment or concern for the patient but the capacity to discern what the patient actually needs and delivering it that bonds the physician to the patient. This sometimes requires the doctor to distinguish between the patient's description of how they are feeling and their actual conditions. As Offri (2004) notes, at times it might mean giving them the space that they need to say something unpleasant or embarrassing—for instance admitting that injuries suffered from a fall are actually the product of spousal abuse. As one physician notes this takes time. It might take the patient until they have their hand on the door knob and are about to leave your office to ask a question or make a statement that illuminates their actual condition—which is also the moment when the physician actually becomes aware of what must be done. Thus, the "bond" we are describing is one that paradoxically embraces empathy and distance, patience as well as the decisive action that comes from keen insight.

Stephen: What we might call caring labor, or dealing with their mentality. It's like a stewardess in an airplane dealing with an unruly passenger.

Dr. Stan: Right, let me give you one example. You see someone really horrible that way and I won't, there's a definite population who is more apt to behave that way and I think I'll just leave that out. So if you are seeing someone who just had a heart attack, maybe suffered a cardiac arrest, and they've regained consciousness and they might look at you, at your little [name of the local hospital] and say "look I want to go to the Mayo clinic right now!" And you want to tell them "look you're going die on the way to Mayo, you can't go to Mayo, we have got to deal with this right here and now!" And that's the message you are trying to convey but you can't convey it that way. You have to learn how to manipulate them. You have to manipulate them effectively and efficiently and quickly.

Stephen: Because otherwise they might die?

Dr. Stan: Sure. And you have to make them happy with their decision. So it's a dance and you may not be in the mood to dance if you are in your eleventh hour of a fourteen hour day but you still have to do it and you have to do it effectively and it's not a matter of selling them a car that you want to sell them, you've really got to help them help themselves and it's takes a lot of... that's where the "con man" comes in. You've got to do it quickly and you've got to do it right and that's not a fun part of the job. (Stan 2001)

I think, finally, it is Dr. Stan's willingness to do whatever it takes to treat his patient the best way that he knows how is what gives us a sense of this relationship between affect, ethics, and duty. Dr. Stan acts out of necessity in a space of uncertainty. It is both the uncertainty of outcome of ones actions and the necessity of choice that defines caregiving, at least in this instance, as a profound ethical act.⁶¹ One thing that strikes us with this example of Dr. Stan's "conning" his

⁶¹ As Žižek (2004b) points out, the physician is in a sense still in the position of the Master—they are on occasion called upon to make irreversible decisions that affect the lives of others. Žižek likens this to decisions made by politicians in a war time situation—Churchill during the blitz. The finality of the decisions we make in this context also underscores that all decisions are made on the basis of imperfect information, under the conditions of uncertainty, which is perhaps why the space of decision in the hospital has such a dramatic quality. While I am sure Žižek would recognize the commonplace assertion that physicians sometimes do act as if they were God, he is trying to make a point quite apart from this. And that is simply that there are circumstances in which human decisions need to be made swiftly on the basis of incomplete information with

patients is that the ethical dilemmas confronting caregivers are different from other problems that we might make in life.

This idea of an ethics of duty in relation to care leaves us with other questions. How can one become capable of making these decisions? How does one rise to the occasion? How can one act decisively, acquire the ability to discern what a patient needs and to act on those needs over the protest of the patient themselves? What, in short, allows caregivers to bridge the divide between patient's "sovereignty" and themselves, to temporarily suspend the law that separates self and other in order to pass to the act of caring?

Ethics and Symbolic Death

These questions suggest to me the relevance of a contemporary discussion on the nature of the ethical act that has been initiated by Badiou (2000) and pursued in a similar fashion by the Slovenian school of psychoanalysis (e.g. Žižek 2000c, Zupan i 2000). The aim of these theorists is to understand the connection between the ethical act, the emergence of the ethical subject, and the event that gives rise to this possibility. The particular connection that the affective intensity of care forges between ethics, act, and event is what will allow us to understand the caregiving subject.

According to Kant, the ethical act is distinct from every other kind of action undertaken. Most actions—buying a newspaper, getting a job, reading a book—are for Kant pathological, not in the sense that they are linked to mental illness or disease, because they are linked to the subject's idiosyncratic self-interest. The

irreversible consequences. From this perspective we place a tremendous social confidence in physicians—we accord them the status of "master." Could this explain the degree of recrimination that occurs when we discover physician error, their self-interestedness or something other than

ethical act in contrast is an action committed by an agent without any pathological motivations whatsoever, that is, without any thought of a return. Kant admits that this conception of ethical action confines it to the realm of the ideal or the formal precisely because no human action is committed without thought of a return, without pathological motivations or a flow between the agent and that which she acts upon.

Zupan i (2000) follows a Lacanian reading of Kant in arguing that there is another way of distinguishing ethical acts from ordinary actions. She argues that the hallmark of an ethical action is that its execution erases the agent who faced the ethical choice initially :

The act differs from the “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. (Zupan i 2000, 83)

The ethical act transforms the bearer by forcing them to transgress man’s law in order to fulfill their perceived sense of duty. This transgression of man’s law is, for the New Lacanians, part of what defines the ethical act: to break the law is to go against one’s self-interest in this instance. One thing that unites these contemporary theorizations of ethics is their tendency to use extreme examples of the ethical acts in order to illustrate their point. The figure of Antigone is used by Copjec, Zupan i , Žižek and others as the quintessential ethical subject. She violates Creon’s law, to leave the enemies of the state un-interred, in order to obey the gods’ law of burying the dead properly, at the cost of her life.⁶²

their infallibility? Could this be the reason, as Adams (1998) asserts, that physicians feel like it is impossible for them to admit their own mistakes and are in a sense not allowed to be human?

⁶² Other examples include Žižek’s (2000) discussion of the Jewish ballerina who, when forced to perform for Nazi officers, grabbed a machine gun from a charmed soldier and proceeded to kill as

The question becomes whether or not this definition of the ethical act and the ethical subject has any relevance to the everyday actions of caregivers? The examples that the New Lacanians provide are extreme moments where the symbolic death of the subject and their literal death coincide. Antigone becomes ethical the moment she chooses to violate man's law in order to obey the gods. She is transformed the instant she chooses to die. These examples might leave us with the impression that symbolic and literal death must coincide for an act to truly be ethical. Is this true? Where caregiving seems to diverge from Antigone's ethical act is that it does not instantly reconfigure the subject nor, in all but a few instances, does it confront them with the risk of death.⁶³ Caregivers face everyday decisions about how to care for the other, how to deal with the stench of illness and infirmity, the dementia of a loved one, the persistent helplessness of another.

many Nazis as she could and Zupan's popular cultural reference to Arnold Schwarzenegger's character in *Terminator 2*—the sentient cyborg that allows itself to be destroyed to prevent the annihilation of the human race.

⁶³ The annihilation vs. transformation of the caregiving subject was recently depicted in Almodovar's *Talk to Her* (2002) and Arcand's *Barbarian Invasions* (2003). Zupan's ethics always involves transgression of the law that only becomes the right thing to do only afterwards. Both of these movies are essentially about palliative care. In *Invasions*, the initially reluctant son "breaks the law" in order to care for his father. He bribes union nurses and contractors into getting better care for his father; he gathers together his father's friends, he pays former students to visit him and, ultimately, he contacts a former lover turned junkie to supply his father with heroin. This move could be seen as an indictment of Canadian health care. In actuality it depicts his son's efforts at constituting a community in order to care for his father, a process that transforms him from a distant and disaffected merchant banker to a loving son. In caring, he reconciles with his father and comes to see the point of his father's life rich with companionship and passion of various sorts. If *Invasions* is about the successful ethical act, *Talk to Her* is about the psychic and physical dissolution of the caring subject. *Talk to Her* tells the story of a male nurse, Benigno who falls in love with his patient—a beautiful comatose woman. Caring for her becomes a deadly lure, an obsessive task. In a moment of magical realism he rapes and impregnates the comatose girl, an act which ends up reawakening her body. Far from being in a position to return his love, the patient is horrified by Benigno's act, and Benigno goes to prison for his crime, where he commits suicide. While much is made of Almodovar's depiction of rape, and the attendant moral ambiguity of Benigno's act, there is another point to be made here. Benigno's obsession became as strong as it did because there was no one in his life, no colleagues or friends, that were really watching over him or preventing him from carrying his identification with the comatose woman too far.

Can we understand the actions that are preformed in response to these challenges as the event that forms the caregiver as an ethical subject?

Ethics and the Event

One cannot help but think here of the role that oath-taking continues to play in the professionalization of physicians the world over. Badiou (2000) argues that physicians who swear to the terms of the Hippocratic Oath agree to treat patients regardless of whether they can pay or not, without thought of whether they are citizen or an enemy of the state, without regard to whether they are young or old, whether they are dying or have hope of recovery. Badiou maintains that fidelity to this ethic, the process of becoming its subject, is what makes a physician a physician. Badiou's vision of the physician as ethical in the Kantian sense revolves around the swearing a vow that confirms and performs this fidelity. Here the speech act of repeating the vow and becoming a physician occur at the same moment. The speech act of swearing is, for Badiou, the event that creates the subject—the physician—while the physician's continual affirmation of this vow is what defines fidelity. The event creates the conditions for the properly ethical actions of the subject; it is the condition of possibility for the ethical subject.

Badiou defines the event more generally as an eruption in the existing order that allows for the possibility of radical transformation. The examples of the event that he provides are marked by a similar extremity that characterizes Zupan i and Žižek's "ethical act." The supreme example of the event for Badiou is the social upheaval of May 1968 in Paris. May 68 was an event that possessed the potential to fundamentally reorder social and political life in France. Fidelity to this tear in the fabric would have not only transformed the agents—students, trade unionists, politicians—but its status as an event depended upon this

transformation. The betrayal of the truth of this event, for Badiou, represents a tragic missed opportunity—a disaster. According to Badiou, radical French thought since May 1968 has revolved around understanding/mourning this missed opportunity.

For Badiou, fidelity to an event is pursuing the course of becoming that it inaugurates, what he refers to as the pursuit of its truth. In the case of the physician he may be faithful to scientific truth and faithful to the terms of the oath that he has taken.

Groopman's experience allows us to understand this transformation—this becoming a subject of care, a caring subject—in more precise terms. The substantive meaning of this oath, to treat all and refuse none, emerges only in relation to an encounter with the particular patient. Being faithful to this process meant one thing in relation to Dan and quite another in relation to Barbara. Likewise, Stan's experience tells us that pursuing the right course of actions as a caregiver involves an intense interaction with the patient, one that forces him to assume many roles in the course of treatment.

Ethics in a Supportive Context: Noncapitalism and Generosity

The oath is a transformative event that allows a physician to act as a physician. Other theorists have commented on the performative dimensions of oaths, the moment where the symbolic identity and lived experience of the individual is transformed by the act of speech—Butler's (1993, 2000) notion of the “performative” and Deleuze and Guattari's (1987) “leap in place” are analogous to Badiou's concept of the event. While this is an important aspect of becoming an ethical caregiving subject, not every caregiver's initiation into their duties is marked by a formal trans-substantiation. What about ordinary people—

housewives, retired policemen, truck drivers—who find themselves, either gradually or suddenly, drawn into the process of giving care? Are these people potential subjects of an ethics of care? Are they faithful to the process of giving care? Are they transformed by the pursuit of its truth?

I have interviewed “ordinary” people who have been transformed as subjects by the event of giving care. I have found in both professional and informal caregivers a confirmation of this connection between the event, the act, and becoming an ethical subject, but also moments where the experience of caregiving causes extreme duress. Becoming a subject of care, the act of caring, remaining faithful to the event that is the cause of this transformation is not easy. While almost all of these people cared for people without the expectation of a return from the people in their charge, they also spoke of a felt need for greater recognition and support from a larger community for the work that they do. Almost to a person, they saw “greed,” the “profit motive” or even “capitalism” as an impediment to effective care, as something that intruded upon the process of being faithful to care. All of these “economic” terms were meant to signify a pervasive pathological self-interest that interfered with the selfless and ethical commitment to duty.

The Kantian ethical subject highlighted in the new Lacanian discourse appears to be a heroic figure who is the author their own actions, capable of perceiving and responding decisively to events as they arise. The caregiving subject may conform to the Kantian conception of a non-pathological actor, but each person I talked to recognized that their fidelity to caring was enabled by support they received from others. Caregiving is not an act performed alone. Far from heroic this makes the caregiver seem ordinary and her actions common

place. Does the ordinary and non-heroic nature of the caregiver's act make it less ethical? Here, I argue, a precise understanding of the non-pathological/ethical act is required. While ethical caregiving is a non-pathological action, an action that is done without expectation of a return and that transforms the agent of the act, it does not follow that the capacity to act ethically comes to the subject *ex nihilo*, nor does such a capacity for action exist in a self-sustaining state. The caregivers I interviewed regard themselves as ethical and generous subjects in their caring labors but recognize that they need support to sustain their efforts. If the capacity for ethical care exists in supportive situations but not in other circumstances it might be important to understand what distinguishes one from the other.

The interviews I have conducted allow me to make a provisional assertion about the way that health care reform can be visualized in relation to the diverse/community economy diagram. The more the circulation of care resembled a freely given gift, the more the caregivers are surrounded by a generous and supportive environment, the more the caregiver is able to remain faithful to their ethics of duty. In the same way, just as an economy of generosity functions to sustain the caregiver, I argue here that non-exploitative class processes (independent and communal) are the class processes most conducive to conceiving of oneself as an ethical subject and pursuing the truth of care.⁶⁴

⁶⁴ In some ways, the process of encountering the beliefs of my interviewees is remarkably similar to the encounter that structured our experience in the course of the REP. While many of my subjects were critical of "capitalism", the "profit motive", "greed," etc., they lacked an effective language for describing an alternative arrangement of social relations in the care sector. The absence of an alternative frame, only being able to articulate themselves in a language of being against something, seemed to be a uniform source of frustration.

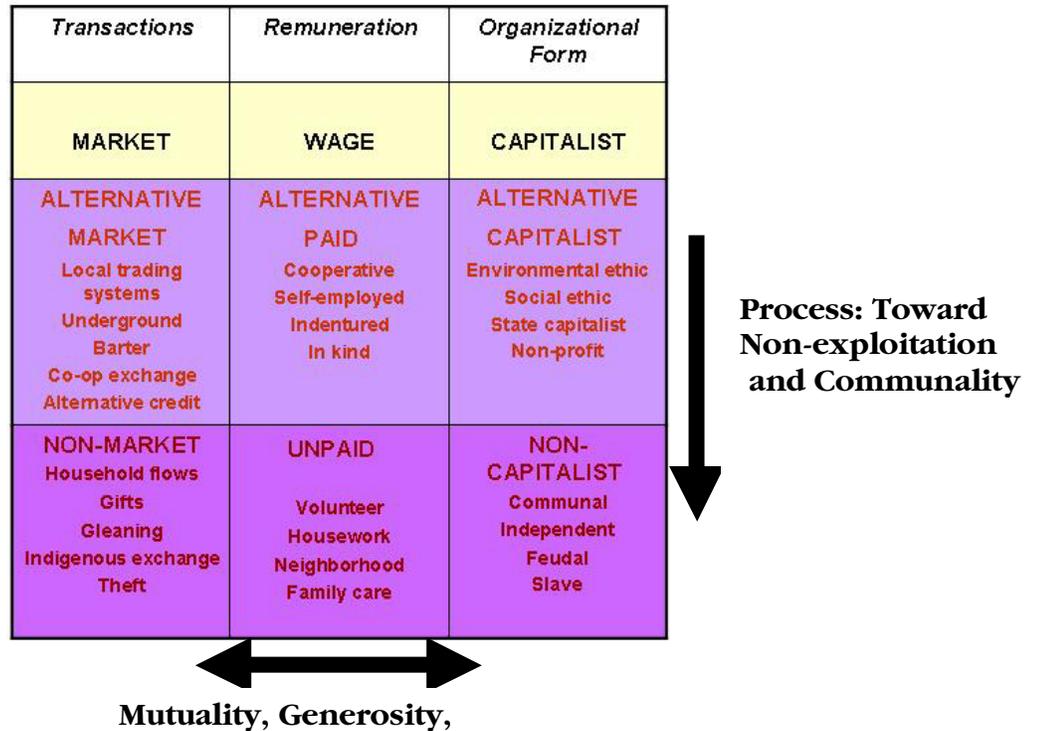


Figure 4.1: Diverse Economy and the New Trajectory of Reform

Two interviewees in particular provide us with a compelling illustration of the Lacanian/Kantian notion of the ethical act: Ashley and Anasuya. Both describe the challenges, rewards, and self-transformation that accompany the work of informal caregiving. Both have definite ideas about what motivated them to do the work they do or did, what got in the way of doing it as well as what might have made their labors easier (or eliminated some of the burden). It is perhaps easiest to recognize caregiving as ethical when it is performed voluntarily, in non-commercial spaces, and given freely. From the perspective of this dissertation it becomes interesting to consider the way in which the status of their unpaid labor as “freely given” and, by extension, their status as ethical subjects was determined by their location in the diverse/community economy, especially in relation to class process.

Becoming a Caregiver: Ashley and Anasuya

Ashley

I interviewed Ashley towards the end of the spring of 2003. My father had recently been diagnosed with a fatal lung ailment and I had come to think of Ashley as an ally in this experience since I had learned earlier that she was a volunteer at an adult day care center in the town of Greenfield. When I asked if she would mind being interviewed about her work, she said that she would be delighted to talk about her experiences.

Ashley was twenty-one years old and looked younger because of her fair skin and red curly hair but carried herself as if she were a much older person, quiet and reserved and yet not at all shy. I began the interview by asking her how long she had been involved in providing elder care as well as what drew her to that particular form of caregiving. She explained to me that she had always been interested in providing elder care and that she intended to pursue geriatric care as a career. I asked her what motivated her at such a young age to spend so much time on caregiving for elders:

Stephen: Yeah. So, what motivates you to do this thing? I mean apart from...if you don't mind my asking that question?

Ashley: Oh, that's fine. People always ask me that question, because they can't imagine why somebody would want to do it. Um, I don't...my whole life I've been around older people, and I've seen a lot of the flaws in either health care programs or things that could improve their life that they're not getting. And I think especially with community programs and things like that, they really help people. And the particular program I worked for, the goal was to keep people out of nursing homes. And as long as they have somewhere to go at night with adult supervision, during the day they could have everything and then some of what a nursing home has. You know, they have the activities programs, the therapy, all that sort of thing. And I've always just wanted to take care of older people. I guess I don't know really, but... I mean I like to think that if I was eighty years old and had Alzheimer's and didn't know where

I was going or where I was coming from, I would hope that somebody would be nice to me, and somebody would take care of me. So, I guess that's why. (Ashley 2003)

At first blush, what Ashley is articulating here does not meet the criteria for an ethical act. She can certainly see the value of adult day care centers which are basically community/volunteer-based alternatives to conventional institutional care for elders, particularly those suffering from age-related neurological disorders. Adult day care centers not only allow the people who receive care to continue to live independently. Their actual purpose, as Ashley explains, is to relieve primary care providers—family members and neighbors—so that they can attend to other obligations, such as paid work, or at the very least to enjoy a rest from the stresses of caregiving. In some sense what I was getting from Ashley was not her ethical motivation for doing this work or how it affected her but its political significance and its significance for community. This articulation of her commitment to care was grounded in terms of an enlightened self-interest—“someday I will be old”-- and with the expectation of a return—“I hope someone would do this for me.”⁶⁵

Further on in the conversation I thought to ask her about the dimension of the aging process that I see as the limit of my ability to identify with people in need to chronic care: the loss of basic functioning, of the ability to feed and toilet oneself, and the humiliation that that loss entails. Ashley's response was remarkable:

⁶⁵ The actual sense I was getting from Ashley at this moment was a resistance to being exposed, a deliberate attempt on her part to keep the nature of her commitments to herself rather than revealing or divulging it. I saw this sort of reluctance or resistance to exposing oneself again and again amongst my interviewees in relation to this topic, even if they were forthright in their discussion with me. The question this leaves me with is what is the source of this modesty when it comes to speaking of one's own personal convictions, or the motivation behind a deliberately ethical act? Does speaking of a bona fide ethical act somehow invite a return, an acknowledgement, which somehow retroactively undoes its status as “ethical”? Does recognition transform an ethical/non-pathological act into an ordinary “self-interested” one?

Stephen: Well, maybe you can share a few thoughts with me about that, because it's just something that I, I think has always been an especially traumatic aspect of the aging process.

Ashley: I think dignity depends a lot on how people react to you. So, for instance, if somebody loses the ability to toilet themselves, if the staff person seems troubled by it or embarrassed... To me, I have no idea why, but I've never had a problem facing the toilet issue. And a lot of people do, and that makes the person that needs to be taken care of very uncomfortable, because they feel like a burden, they feel helpless.

Stephen: Or humiliated.

Ashley: Humiliated. So, a lot of it is the way you react to them. If you act like it's no big deal, it's not a big deal.⁶⁶ (Ashley 2003)

Ashley seems to be reflecting here what Gropman and others have articulated about how the nature of the affective bond between patient and care provider can help shape the experience of receiving care, to shape the attitude of the person being cared for. Toward the conclusion of the interview, Ashley spoke of how people cannot accept the loss of dignity and autonomy, nor should they. The challenge to caregivers is to help geriatric patients to redefine their sense of the meaning of those terms so that they can accommodate help from others. This idea of caring as an attempt to redefine the meaning of autonomy and dignity strikes me as parallel to Freedman's use of the Talmud. In fact, Ashley wrote a series of articles on this subject and gave regular classes to adult informal caregivers on how to negotiate this dimension of the caregiving process.

⁶⁶ I should note that other interviewees offered me different insights into how one might accept the aging process and, as Sen (1999) might put it, the loss of capabilities that accompany it. Cindy, a critical care nurse who works in the neurology ward at a local hospital, had also helped nurse both her parents into death. She said that watching her parents deteriorate was very sad for her but seeing a young person in her charge with brain damage from an injury or substance abuse was really tragic. It reminded her of a placard that sits on the wall of her own doctor that was, evidently, put there to put things in perspective for his older patients—"Aging is a privilege denied to many."

In reflecting later on what Ashley said in the course of her interview, I was reminded of Amartya Sen's (1999) attempt at recuperating the notion of human and economic development. His aim was to link the notion of development to an expansion of people's substantive freedoms—the capability set of things they were empowered to do. In relation to international economic development, Sen's argues that development efforts should be evaluated not in terms whether they promote economic growth but as to whether or not they expand the capabilities of the people being subject to development. One could easily imagine this criterion being applied to health care as well. Does any particular health care intervention restore, increase, or retain the capability set of the patient?⁶⁷

Ashley seems to complicate Sen's notion of development by suggesting that the capability set of a person can shrink as well as expand. This is a fundamentally difficult aspect of the aging experience. She pointed out to me that it is not only the patient that has to accommodate themselves to the task of redefining autonomy and dignity, to the loss of certain types of independent functioning, but also caregivers themselves. From the perspective we have adopted here, however, this leaves us with a compelling question: how is it that a twenty-one year old woman could come to such an understanding? Why is she so comfortable with this proximity to loss?

Stephen: Yeah, so you feel like you just naturally fell into that attitude of just not thinking it's a big deal. Is there any effort, I

⁶⁷ Indeed this is, in a sense, the standard attached to evidence-based medicine, the simple insistence that any course of treatment should be evaluated in terms of its efficacy. One example of this might be the discovery that the extended hospital stays of new mothers do not substantially increase their chance of recovering from the process of child birth. It was on the basis of this observation that post-delivery hospital stays have decreased in duration from a week to forty-eight hours or less in the absence of complications.

mean, is that something that can be learned? Is that a part of someone's socialization repertoire on the job?

Ashley: I'm not...I don't know how I feel about that. I mean, I've known CNAs that hated it at first. But it takes some getting used to. And then it doesn't bother them any more. But then some people, it will bother them. And I think it is because of just the way they grew up.

Stephen: Yeah, sure, it's essentially a cultural taboo. (Ashley 2003)

Here Ashley recognizes the distance between herself and other caregivers, even those operating as professionals that have not gone through this process of getting used to the decline of bodily autonomy and privacy. It was at this point in the interview that there was a change in Ashley's tone. Her appearance of "clinical reserve" broke down as she reflected on what it was in her life that led her to have this capacity as she began to detail an experience within her family that fundamentally transformed her as she was finishing high school at about age seventeen.

Ashley: I think the other reason it doesn't bother me...How long ago.... Three years or so, my grandmother, she broke her back, went to the hospital, they gave her an antibiotic that So she got up on a step ladder as I was on the way over there to help her put the curtains up but she couldn't wait. She had to do it herself. So, she fell, went to the hospital. They gave her an antibiotic, because they thought she also had pneumonia and that was why she lost her balance. But she didn't have pneumonia. The antibiotic caused her to have colitis, which eventually killed her.

Stephen: You're kidding. Well, I guess that makes sense because it would just...even in a healthy, a young person, antibiotics can affect your intestinal flora.

Ashley: Yeah. And so she had colitis, and with colitis she totally lost all control. And you know, she broke her back, so she couldn't get up and move in time, and the vertebra didn't totally break. It just split on one side, so there was nothing they could give her beside a back brace, but that was it. So she would be bedridden, and she refused to use a bed pan or anything. She wanted to get up, she wanted to make herself get better. So every single time she got out of that bed, it was an accident. So it was up to my mother or

myself. We took turns taking care of her. My stepfather too.
(Ashley 2003)

Ashley began to discuss this formative moment well past the half-way point in the interview.⁶⁸ In some sense the order of this recollection, her hesitation to speak of this deeply affecting personal experience, the tears that welled up in her at this point in the interview were all obvious signs that we had hit on an event that made Ashley who she is—orienting her desires and directing her towards a particular vocation. It was as if we had arrived at the point of origin of the Ashley that is now. Would she be the person I interviewed if this event had not happened?

It was at this point that it occurred to me that she was young at the time and may not have felt entirely free to refuse to care for her grandmother. This might have been an obligation put upon her by her mother or stepfather.

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

Ashley: No, not at all.

Stephen: 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 2003)

Ashley, at age seventeen, learned to be unconcerned with the literal shit of the other. While Ashley felt that she was not coerced to care for her grandmother, her grandmother saw things differently. In Ashley's view, her grandmother on the one

⁶⁸ I sensed that it took Ashley quite a while to share with me the significance of this obviously emotional event in her life. As much as Ashley is a dedicated volunteer at the adult day care center she clearly had formed a professional persona in relation to this experience, as someone that kept a certain distance between herself and the difficult things that she had to deal with

hand refused to see herself as dependent while on the other assumed her daughter and granddaughter could, naturally, be expected to care for her. In a sense her grandmother's attitude was radically contradictory—I don't need any help, and I shouldn't have to ask you for the help that I need or be grateful to receive it. Later in the interview Ashley explained that her grandmother's attitude originated with certain sexist expectations.

Ashley: She was very sexist. My mother had an older brother, and it was all about him. She didn't do anything for her daughter, didn't want to send her to college, didn't want.... because you know you don't do that for girls.

Stephen: It was good enough for her to get married or whatever.

Ashley: Yeah, and my mom did go to college eventually, but.... So, and she always treated women like they were next to nothing, even though she was one, which is kind of ironic to me. So, I guess we weren't very much in her eyes her whole life. But what it comes down to is somebody in your family needs help, you have to do it. So we just picked up right there and....

Stephen: So, you used the language of an obligation there. It's family, and yet it's something you don't experience as obligation, but something beyond that. Like necessity, or I don't even know what the word is for that.

Ashley: I think it's an obligation, but at the same time, many people refuse to take it as an obligation or to take responsibility. For instance, my uncle, even though he got most of the family resources growing up, and even in adulthood he was the king of the world, he never did anything, never helped them. I mean, my grandmother was seventy-three by the time she died.

Stephen: Perhaps because he was so used to taking that he wasn't socialized into reciprocity.

Ashley: Right, yeah. So I mean, we mowed her lawn, we did all her stuff that she couldn't do any more after my grandfather died. But when she became ill, to me it didn't matter what type of person she was. It should be an obligation for the family to do as much as they

there—people's decline and death. This might also explain her apparent reluctance to reveal such a personal and affecting experience.

can, but at the same time I just saw it as that's my grandmother and I want to take care of her. (Ashley 2003)

It is here that Ashley's sense of why she, her mother, and stepfather were caregivers gets more complicated. They felt obliged to care for her while the son who had enjoyed every advantage did nothing. Felt obligation and gendered expectations regarding care raises the question as to whether Ashley really is a free-ethical agent or someone compelled to engage in caring labor. Further, does feeling obliged to do something automatically reduce the subject to a pathological (as opposed to ethical) agent?

Ashley says in her interview was that it was both that she felt obliged to do this work and that she wanted to do it. One argument that could be made in favor of viewing Ashley's act as ethical—performed without expectation of a return—is that she already knew her grandmother was “not a nice person.” Ashley cared for her grandmother knowing that this care would not necessarily elicit appreciation or acknowledgement in return. However, this only partially answers our question—one can feel compelled to obey despots. Ashley also recognized that the nature of her relationship with her grandmother changed over time. Towards the end of the interview Ashley spoke of the beginnings of a change in her grandmother's attitude:

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.

Stephen: 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. (Ashley 2003)

According to Ashley the deterioration of her grandmother’s condition was accompanied by a gradual opening up to receiving the help of other people without protest. This shift had important implications for Ashley, teaching her that there is a process involved in the patient coming to accept the loss of functioning.

Ashley: I guess the only real way to get over it or get someone to understand that it’s okay to lose abilities, and that they can still be the same person or still be a dignified person.... it is just to keep reinforcing that whatever you need, it doesn’t matter, you know, and there’s no shame in it. But it takes a while, definitely. (Ashely 2003)

It is here that the adult day care center as a social institution might play a decisive role. Ashley explained that the adult day care center does not simply allow caregivers a break or a chance to work on other things. Caregivers can go there and learn how to be more effective, less stressed, or negatively affected by their experience. The center makes sure that caregivers aren’t burning out and, at the same time, ensuring that their patients are not being abused or neglected.⁶⁹ The day care center is as much about caring for the caregiver as for the person suffering from Alzheimer or dementia.

I asked Ashley what it would take to make these adult day care centers more effective and to think more broadly about this issue of reforming elder care.

Ashley: I think that’s basically the biggest thing that’s lacking in institutional care, and you know hospitals, that sort of thing. There’s just too many clients per staff. You can’t get to know them, you can’t even...you barely have time to run over and give them their meds every few hours, let alone spend time talking with them.

⁶⁹ As Patch Adams observes, it is precisely the feeling of being “indispensable” to another person that causes caregiver burn out. For this reason, caring for the caregivers is important because it is what allows for them to retain an affective reserve.

Stephen: Can I ask you to think about this both for you and more broadly What kind of things could help this kind of care or this particular context for delivering care to be more effective? I mean, obviously, more funding would be one thing.

Ashley: I would say, I mean I guess it all boils down to funding. But to take the perspective off of just sustaining life and focusing more on keeping a high quality of life. Because no matter what age you are, you're not just somebody that goes to the doctor or takes pills or, you know like a lot of nursing homes, the patient could sit in their room all day and not do anything, but get their meds every few hours and have their blood pressure taken. But focusing more on the personal aspects for emotional health I guess would be most beneficial.

Stephen: So it's almost like the nature of the commodity has to change.

Ashley: And I mean there's been a million studies done on people that you know are unhappy in the end of their life will die faster than people that are more hopeful, have a broader social support network. Especially with married couples: one dies, and if that was the basis of their social support, then they'd die very soon after. (Ashley 2003)

Here, at the conclusion of the interview Ashley seems to be connecting two interrelated points about adult day care centers. The first point is that this center allows informal caregivers a better chance of being able to experience the caring labor they do as something they want to do even as it remains necessary. The second point not to be missed here is that the day care center changes the prognosis for people with neurodegenerative diseases like Alzheimer's in enlarging the social circle that surrounds the patient.⁷⁰ In what way might this be related to

⁷⁰ There is, of course, something of a missed opportunity in simply discussing how the process of being an informal caregiver transformed and, in a sense, created Ashley as a subject. Ashley also had quite a bit to say about how this grant-driven adult day care center was run. The budget for staffing the place was pathetically small. It could not have functioned successfully without a steady input of labor from the volunteers. Similarly she described how the program director, and then Ashley herself, were continuously scrounging (or purchasing out of pocket) materials for craft projects, small pets, for the day care center and other things that made a nurturing space of the sort described by McCourt (2004).

Groopman's observations about the peculiar nature of hope and its context specific meaning?

Perhaps what ultimately emerged from my interview with Ashley is a recognition that both the dignity and autonomy of the patient and the ability of an informal caregiver to feel fulfilled in their duties are the effects of an encounter that is continuously restaged. While a sort of persistent re-enforcement is required, in Ashley's view, to make someone accept a loss of basic functioning, it is equally true that the support an informal caregiver may or may not receive plays a large role in shaping how they experience the process of care. There is an interconnection here that needs to be explored.

Anasuya

I interviewed Anasuya in mid December of 2004. Anasuya is in her early fifties, a mother of three adult children and an active grandparent of three grand children.

I have known Anasuya for a number of years as a colleague. During that time she had been involved in coordinating care for her husband's mother Cathy. Anasuya describes Cathy as a very independent but perennially depressed divorcee who was never particularly close to her children. While her husband has a sense of duty towards her as his mother, Anasuya assumed the task of coordinating care for Cathy and visiting her during the time that she spent living in assisted living and nursing facilities in Western Massachusetts.

In 2002 Anasuya had received a phone call from her sister-in-law who explained that Cathy, who had recently moved to the suburbs from her apartment in downtown Chicago, was in a terrible state. She had decided that Cathy couldn't be left alone, that she couldn't return to her house in the suburbs. Not knowing

what else to do, the sister-in-law brought her to a hotel in downtown Chicago before calling Anasuya. Anasuya and her husband boarded a plane the next day, flew out to Chicago, packed up most of Cathy's important belongings and then convinced Cathy to come back east with them.

Three days later, Cathy said that she was better and ready to go home. After a few futile attempts at convincing her to stay, showing her some assisted living places which Cathy rejected out of hand since they were full of "old people" (unlike herself), Anasuya and her husband put her on a train back to Chicago. Things went fine for several months until the fall of 2002 when Cathy had what Anasuya described as a nervous breakdown. A doctor remanded her to the care of a large assisted living facility in Chicago. After a few weeks of making phone calls to Anasuya several times a day to complain about how horrible life was in this new place, Cathy adjusted and even became romantically involved.

In the Winter of that year things took a turn for the worse. Cathy developed a bladder infection which caused her to lose her grip on sanity. The care facility responded with sedation and restraints to control her. Eventually Anasuya was contacted by a friend who had been to visit Cathy.

So we flew out there again and we decided that we couldn't keep going out there because it was crazy expensive. We saw that she was in a really really bad place. She didn't know what was happening and she was totally incontinent. We decided that we should get her back here and then we found a place. It was small. They were willing to let her be in the independent care facility. It was small and kind of provincial compared to what she was used to. We weren't about to take no for an answer so she stayed there for most of the year. [2003]. She was happier than in other places though she complained all the time. (Anasuya 2004)

By Anasuya's estimate, she spent approximately ten hours per week with Cathy, mostly as her companion, but also in dealing with issues surrounding the

financing of her stay at Loomis (\$7,000 per month).⁷¹ Much of her time with Cathy was spent taking her around the Valley, keeping her company, and listening to her complaints with good grace. According to Anasuya, one of the effects of Cathy's dementia was that other sorts of diversions—reading, listening to the radio, watching TV—failed to hold her attention. Human companionship and “conversation” were the only thing that held Cathy's interest and an intense loneliness and disorientation overcame her when she was by herself.

In April of 2004, Cathy began communicating with one of her friends in Chicago—a woman in her mid-sixties whose own mother had suffered from dementia. Cathy and her friend became convinced that she would be better off in Chicago. Anasuya believes that Cathy's friend, Miranda, overestimated Cathy's capacities because she was fooled by her act of being competent and “with it.” After a torrent of relentless phone calls from both Cathy and her friend, Anasuya and her husband relented. They helped Cathy move back to Chicago and held her space at Loomis nursing home for an additional month.

Cathy placed a tremendous financial and temporal burden largely upon Anasuya but also upon other members of her family. In spite of this Anasuya seemed to have an apparent sense of humor and grace, both about her time spent caring for Cathy and also Cathy's ultimate refusal of this care which Anasuya freely offered. In part this is an effect of Anasuya's thirty-year practice as a Buddhist which has, as she put it, taught her compassionate acceptance of people as they

⁷¹ Of course this raises the question of where this money was coming from. Cathy's rehabilitative care expenses, which allowed her to recover from her first fall, were paid for by Medicare but her housing in these various nursing facilities was an expense that she was in a position to shoulder because she had inherited a considerable sum of money from her own parents. Likewise, Anasuya's family was in a financial position to be able to fly out to look after Cathy, etc. Things

are. This is what allowed her to not see Cathy's move back to Chicago as rejection of her or the gift she (attempted) to give her. Fearing I had missed this point, I received a call from Anasuya after her interview.

I really like Cathy, even though she can be a pain, she can be quite fun at times and even when she's not intending to be can be a real hoot. She has quite a good sense of humor and I think that has really helped her deal with her depression and she has some understanding of her diminishing capabilities. Like one time I was talking to her about occasional incontinence (she had just peed on my porch chair earlier that day and we were on the way back to the nursing home), and she basically told me that sometimes she just has to pee and doesn't feel like getting up and when I asked her about going out like to a restaurant she said that that was other people's problem. Sometimes her demented rantings were very humorous, and I also had a lot of compassion for her basic feeling of loneliness so I wanted to help her if possible. It was possible for me to enjoy her company in a way that my husband couldn't and of course I wanted to help him out too so it just worked out. My motivation was therefore multiple. (Anasuya 2004)⁷²

Anasuya spent a lot of time talking about her closeness with her own children as part of what enabled her to be so caring for Cathy, a woman who had never been very close to anyone and who was no longer fully capable of appreciating or acknowledging what Anasuya was doing for her.

would have been quite different if Cathy and Anasuya's financial circumstances were not so fortunate.

⁷²In reflecting on the support that she receives, Anasuya ended up spending quite a while talking about the role that food—its preparation and consumption—play in what makes her own family/community pleasurable. She observed that while food is the center of life in the community that she is a part of, institutions frequently “get it wrong.” In response to the same question I asked Ashley—what would enable you to do care more effectively, what might health care reform actually be?—Anasuya responded that institutions like nursing homes should be built from the kitchen outwards.

Another model approach she told me about emphasized family care. She told me of one family whose four children take turns, three months out of the year, to care for their grandfather who enjoys being able to spend time with each of them without becoming a burden. This model seemed to appeal to Anasuya who thought that three months would be just the right amount of time to spend with anyone.

Unpaid Caring Labor, Provisional Conclusions

Both the stories of Ashley and Anasuya tell us a lot about the connection between the affective intensity of caring labor and the capacity to make an ethical commitment. The interviews done in connection with the Rethinking Economy Project make it clear that Ashley and Anasuya are not alone in placing their commitment to informal caregiving at the center of their lives. Other interviewees spoke of how remaining in the Pioneer Valley or the decision to move back there was based on the necessity of providing informal care to a parent or loved one. In other words, people make major life decisions in relation to their duties as informal caregivers (CEC 2001 a, CEC 2001 b).

We can recognize Anasuya's and Ashley's actions as ethical because the care they gave was given freely, without an expectation of reciprocation, and that providing this care transformed them as ethical agents. While Ashley felt obliged to care for her grandmother, the fact that elder caregiving became her vocational commitment is what makes a compelling case that Ashley was transformed by this experience with her grandmother. Likewise, the fact that Cathy could not really give any recognition in return for the constancy of Anasuya's company and continual effort is what allows us to see Anasuya's actions not as pathologically self-interested but rather as an ethical act in the way that Zupan *i* describes it. Anasuya's caring labor remains an ethical act even if the reason she cared for Cathy was, in part, her love for her husband. Kant himself saw the ethical subject as a formal/ideal category that the actions of actual people could approach only asymptotically but never finally achieve. The stories and actions of Ashley and Anasuya are what convinces me that the notion of the "ethical subject" is not simply a formal category but describes an actual process of subjectivation.

Without taking away from the fact that each of these women chose to behave ethically, to engage in this process of caregiving, each of them was very aware that a definite set of social circumstances enabled their fidelity to this commitment. For Anasuya, it was both the support from her family and Cathy's financial assets that enabled her to provide the caring labor for Cathy. The lesson that Ashley learned from caring for her grandmother is that her family needed the support from the larger community and that is what led her to become involved with the adult day care center.

Ethically committed caregiving is not an act of individual heroism. Caregivers need support in order to be faithful to the process of giving care and this, in part, is what allows them to be transformed rather than destroyed by its affective intensity. For Ashley and Anasuya, the social conditions under which they labor make it possible for them to think of the care they provide as a gift rather than an obligate duty.⁷³ How are we to more fully grasp this connection between the social conditions of care and the connection between the giving of care and the transformative effects of the ethical act? I believe that class analysis provides us a language to link an ethics of care with its social, economic and material conditions.

Unpaid Caring Labor and Class Analysis

I would argue that the support that each of these women received has implications for how we theorize their caregiving activities in relation to the diverse/community economy concept, especially its class dimensions. While

⁷³ This is not simply a matter of perception or attitude however. What I am attempting to argue here is that it is the social conditions in which this labor is performed that confer upon it the status of "gift."

informal caregiving may be given as a gift or in fulfillment of an obligation it is also a productive of labor—and this is precisely what allows us to think of it in relation to class process.

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
MARKET	WAGE	CAPITALIST
ALTERNATIVE MARKET Local trading systems Underground Barter Co-op exchange Alternative credit	ALTERNATIVE PAID Cooperative Self-employed Indentured In kind	ALTERNATIVE CAPITALIST Environmental ethic Social ethic State capitalist Non-profit
NON-MARKET ♦ <u>Household flows</u> ♦ <u>Gifts</u> Gleaning Indigenous exchange Theft	UNPAID ♦ <u>Volunteer</u> ♦ <u>Housework</u> ♦ <u>Neighborhood</u> ♦ <u>Family care</u>	NON-CAPITALIST Communal Independent ? Feudal Slave

Figure 4.2: Ashley and Anasuya’s Place in the Diverse Economy

♦=elements of the diverse economy that form Ashley and Anasuya’s community economy

As I mentioned in chapter III class analysis, as it has been developed by AESA, is an approach distinct from other strands of the Marxian tradition. Class analysis attempts neither to define groups of people as members of a class, distinguished from one another by wealth, power or income, nor does it imagine Marx’s class categories, slavery, feudalism, ancient (independent), capitalism and communism, describing a narrative arc of historical development. Rather each of these class

processes is theorized as existing in the present and further, that a given individual might be involved in several different class processes (Gibson-Graham 1996). Class processes are distinguished from the other by the conditions under which surplus wealth is produced and by whom this wealth is received or appropriated. In Marxian theory, appropriated surplus wealth generated by productive economic activities (in any class process) is subsequently distributed in such a way that it secures the conditions of existence for perpetuation of the class process (e.g. Resnick and Wolff 1987; Gibson Graham 1996). Here one can think of the way that General Motors depends upon access to financial capital or the work of advertisement agencies in order to bring its product to market. One implication of the dependency of a class process on other enterprises and social institutions that provide conditions of existence is that class processes are inherently unstable.

For instance, as we learned in chapter III, what defines capitalism as a class process is that it employs free wage laborers in the production of goods and services. The wealth that is produced by these workers is received (appropriated) by a group of non-workers (a board of directors in the case of a joint-stock corporation for example). The board of directors can, with varying degrees of autonomy, determine the distinction between necessary labor and surplus labor.⁷⁴ Determining the socially necessary labor time specifies the amount of value that socially reproduces the worker (their wage) and, by extension, the amount of

⁷⁴ Far from being a convergence between supply and demand curves, the wage for various occupations is seen in Marxian theory to be partially determined by *n* number of factors—prevailing laws and social norms regarding compensation, how a particular task is gendered, the presence or absence of unions, etc. The socially necessary value of labor time in turn, can have an impact on the viability of a particular enterprise.

surplus that is available for appropriation.⁷⁵ The board of director's chief responsibility is to distribute the appropriated surplus wealth in a variety of ways that will secure the conditions of existence of the capitalist enterprise. Surplus may be distributed to service loans or to pay dividends to shareholders, for example. New needs for surplus can arise continually, affecting ultimately the amount left over that we prosaically think of as profit.⁷⁶

One thing that is distinctive about the AESA notion of class analysis is that it, unlike elaborate descriptions of social class, is typified by its theoretical "thinness" (Cullenberg 1992). This under-theorization has been developed quite deliberately so that the class theorist is able to see a particular class process and its conditions of existence in its particularity. AESA's notion of class is, in this way, resistant to spatial generality. One consequence of this commitment to thinness is that class analysis usually focuses on a particular site—a state enterprises, household, manufacturing firm, farm, shipping business—and processes—educational services, child rearing, automobile production, tobacco farming, produce delivery etc in their analysis. The boundaries that separate one site or process from another are not always clear and, for this reason, important choices

⁷⁵ To be sure, it is possible for the value of socially necessary abstract labor time (wage) to diverge considerably from what is actually required for the reproduction of the worker. For instance social conditions may arise where employers are able to pay workers considerably less than what is required for reproduction. The Maquiladora's in the 1980s was the site of such super exploitation. On the other hand, in certain industries where unionized labor is exceptionally strong, it is possible for workers to exert monopoly power over labor. In this case, in addition to redefining the value of the labor they are in a position to exact a portion of the surplus from their employers as well.

⁷⁶ For example it was necessary in the mid-1990s for firms connected with the insurance industry to spend significant sums of money to produce the "Harry and Louise" ads that helped to derail the Clinton health care reform plan. This would be an example of a coordinated effort on the part of the insurance industry and the other opponents of the Clinton plan (the National Association of Independent Businesses) choosing to spend a portion of the surplus wealth to create an ideological environment that—they perceived—would ensure the continuity of their enterprises.

are made when a class analyst identifies the particular site or process to be investigated.⁷⁷

Because of their status as unpaid laborers Anasuya and Ashley are not involved in a capitalist class process. At the same time, we can say with certainty that they are not enslaved. From a class analytic perspective, slaves labor without freedom of contract, are dispossessed of their bodies and their entire product is appropriated by the slave master. What is returned to the slave for their reproduction as a labor force is entirely at the discretion of the master.

From a class analytic perspective there are three remaining ways that we might categorize Anasuya and Ashley's caregiving labor: feudal, ancient (independent) or communal. Like capitalism and slavery each of these class processes is defined by the particular way in which surplus is produced, appropriated, and distributed as well as the social conditions that might support or undermine each process. From our perspective, situating Ashley and Anasuya in relation to one or the other of these class processes will have a profound effect on whether we can regard their actions as ethical. In attempting to situate Ashley and Anasuya's caring labor in relation to class process, it becomes apparent that we lack necessary information to truly understand their work in class term. Indeed, Anasuya and Ashley's work could be theorized as an example of each of the remaining class processes.

⁷⁷ This is of course not to say that the class analyst cannot conceive of how different sites and processes affect one another or the way that law, governance or cultural norms might influence what class process prevails in what social location. For instance Resnick and Wolff (2002) argue how governance in the Soviet Union led to the predominance of state-capitalist (rather than communal) enterprises in every sector of the Soviet economy from agriculture to hospitals. The workers in these sites were not involved in the process of appropriation and distribution of surplus wealth (these being performed by a bureaucrat instead). What should be noted here, however, is that the connection between the class process in a particular industry or sector and the larger social conditions are produced through the analysis rather than being presumed.

Feudal Caring Labor?

Ashley and Anasuya could readily be theorized as feudal, in part because of the “feminine” nature of the work they are performing. The feudal household in contemporary America, like the feudal manor in Europe, is a distinct class process (Fraad, Resnick and Wolff 1994; Resnick and Wolff 2005). While the serf in a feudal manor is possessed of their own person they are obliged to work for the lord of the manor either through a sense of felt obligation/debt (and, when all else fails, through a show of force). A feudal serf may labor in the field for themselves for three days and turn the produce from the other three days of labor over to the stores of the lord. The lord in turn provides religious instruction for the serf in addition to seeing that they are protected and that the infrastructure of the kingdom is intact. The wife in the traditional household performs the domestic labors which are then appropriated by the husband (or patriarch) who in turn distributes it to other members of the household. The husband is expected in the traditional feudal household to protect his family from harm and to provide conditions of existence for the feudal household class process.

Clearly Anasuya’s was motivated to care for Cathy by her love for her husband who supports her financially. Likewise, Ashley spoke of the gendered expectations that prevailed in her household—her grandmother expected the women in her household to care for her and felt they should not have to be asked to do so. In Anasuya’s case her husband would essentially be seen as the feudal appropriator who was directing that a certain portion of Anasuya’s labor power be directed to the care of his mother. In effect he would be seen as distributing some portion of her household labor to his mother in order to fulfill his filial obligations. This might have the effect of legitimating his status as the head of household.

Ashley's situation is a bit more difficult to read as feudal in spite of the fact that she and her mother felt obliged to care for their grandmother. It might be possible to see the grandmother herself as the family matriarch—essentially compelling her daughter and granddaughter to labor for her. In this case, it was precisely her “refusal” of help that legitimated her position as the appropriator—“I don't need help and even if I did I shouldn't even have to ask.”

This feudal reading of Anasuya and Ashley's caregiving labor situates this work as a part of a larger household class process. Labor that might have been expended on others or in other domestic activities is either being re-directed to caring labor or distributed to the recipient of the caring labor in the form of a “gift” from the feudal appropriator. Designating Anasuya and Ashley as subjects of a household based feudal class process has some important implications for our argument about the ethics of care. Serfs in a feudal relationship perform labor in the expectation of a return. The lord cares for them and protects them or, at least, does not harm them. As a result their acts of care would have to be seen as pathological rather than ethical, coerced rather than freely given. The feudal class process depends upon feelings of obligation or indebtedness in order to function. I believe that Anasuya and Ashley would not have persisted in their caring labor if their labor was solely motivated by obligation.⁷⁸

Its is not that feudalism forecloses absolutely on the possibility of ethically-driven care but rather that it might make ethical fidelity difficult to sustain. While they both spoke of caring for their charges in relation to necessity, it was a

⁷⁸ The only evidence I can offer in support of this conclusion is the deep personal meaning Ashley and Anasuya attached to their care giving labor as well as their belief that it was a work they freely chose to do.

necessity that they felt free to attend to. For this reason, we must consider their labors in relation to the two non-exploitative class processes: independent and communal.

Independent Caring Labor?

Ashley and Anasuya could be seen as self-appropriating independents producing caregiving services outside of the market context. We could theorize their caring labor as a class process distinct from whatever class process might prevail in their household. In the independent class process the same person who is engaged in productive activity is also the first recipient of the wealth and is, therefore, the person who makes decisions as to how to distribute that wealth. Ashley and Anasuya would have to be seen as producing caring labor (separate from the household class process) for themselves and then donating a portion of this physical and affective labor to their charges as a gift. This would allow us to see the caregiving as an ethical rather than a pathological act since it is done without expectation of a return. There is however a theoretical problem with this analysis. Both Anasuya and Ashley said that their effectiveness as caring laborers was connected to the support they received from family and the broader community. This suggests at least the possibility that Ashley and Anasuya were involved in a communal class process.

Communal Caring Labor?

Ashley's care for her grandmother could readily lend itself to being theorized as part of a communal class process. She clearly was an equal partner in coordinating caregiving with her mother and her step father. It would be a matter of theoretical investigation whether we would regard this caring labor as a communal class process separate from their household or as a class process unto

itself in which care was produced collectively while the entire product was given to the grandmother as a gift. In the same way, we would need to know more if we were to theorize the adult day care center as a communal process in which a voluntary effort was being used to produce a service that was then consumed by the community itself.

It is perhaps more difficult to see Anasuya as involved in a communal class process. She saw herself as the primary care provider for Cathy and that what she received from her children, husband and other members of her family was occasional help and constant emotional support. Perhaps a radical interpretation would be that Anasuya is part of a household based communal class process that collectively produces and consumes care in different forms. Here Anasuya's care for Cathy is really a function of care producing activities going on in a variety of other locations that, *en toto*, compose the communal class process. Here caring labor and the production of community itself becomes the object of class analysis.

A New Approach to Reform: Generosity and Communality

Our understanding of both the site and process of Anasuya and Ashley's caring labor affects both how we might locate their work in class terms and how much this work reflects an ethical (rather than a pathological) commitment. Regardless of how we theorize their activities in class terms, Ashley and Anasuya's labor produced a use-value that was consumed by the person in their care. Ashley and Anasuya both said they at once felt obligated to care and also that they wanted to provide it. Perhaps, the class analyst should initially respect this central ambiguity at work in their notion of duty and risk attenuating the boundaries between exploitative obligate relations and care that is produced under non-exploitative conditions. It is entirely likely that they experience this work

sometimes as burdensome imposition and at other times as joy that comes from giving of oneself freely. Ultimately, however, it was their steadfastness in assuming and being affected by this duty that allows us to imagine caring as an ethical act. If and ethical fidelity to duty is possible under a variety of class processes, then which class process is most likely to leave caregivers feeling fulfilled rather than exhausted?

While the independent/communal class process partially shapes the ability of Anasuya and Ashley to negotiate the affective intensity of caregiving as ethical subjects, it also allows us to see the beginnings of a new political approach to the politics of health care reform. The National Family Caregiver Support Act passed into law in 2000 recognizes many types of informal caregiving and attempts to support it by making information available about support services run by non-profits and volunteer based organizations.⁷⁹ In addition, caregivers are provided with tax credits for their efforts. These responses are helpful to some but not all caregivers. One wonders how this will support caregivers who are removed from the labor force, or who were never in the labor force, and might not have a taxable occupation in the formal economy?

Some critical geographers worry that recognition of the informal caregiving sphere will have the perverse outcome of justifying the further erosion of the state and federal government's commitment to health care provisioning (Joseph 2002). From a class perspective—the withdrawal of state support might have negative consequences for the household class processes. As Pavlovskaya (2005) argues the increasing demands for informal elder care in the context of diminishing public

support might lead to an increase in the rate of exploitation of the informal caregivers or even a class regression from independent and communal to a feudal class process. It might also diminish the capacity of informal caregivers or even increase the possibility of elder abuse, for instance.

The growing demand for elder care, in the context of diminishing governmental support, might lead to a further segmentation of the health care market. Hamilton (2005) describes the way in which progressive nursing homes have begun to provide a cooperative home like environments at premium pricing. On the one hand this is perhaps an ironic valorization of the diverse-economy when “home care like environments” becomes a luxury commodity out of reach of most retirees (Hamilton 2005).⁸⁰ Just as high end care services might be delivered to those who can afford it, one could easily imagine a future where low income elders have only their family as a form of support.

Classing Anasuya and Ashley alerts us both to the way in which their capacity to act ethically could be either enabled or undermined by the class process they are involved with. The household class process in turn is shaped and directed by the social and economic conditions in the greater society. Through this same theoretical approach we might also imagine how volunteer-based community organizations of the sort that Ashley was involved in might be the basis for a political response at the community level. How these organizations are organized—in class terms—might have an effect on how well they are able to intersect with and serve the interests of the community. These organizations could

⁷⁹ <http://www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp> was established as an informational clearing house for organizations, government programs that are designed to help family caregivers.

not only be a way of sustaining or even augmenting the capacity of informal caregivers, they might become new social sites in which to experiment with care delivery. These alternative social sites might provide a sort of common ground that would link informal caregivers with providers employed in the formal market sector—from physicians to alternative practitioners. I will explore this theme further in chapter VIII, but in the subsequent chapters V and VI, I wish to consider the way that alternative and mainstream medical practitioners form themselves as ethical subjects in relation to the process of caregiving.

⁸⁰ While Hamilton (2005) describes elder care services that attempt to reproduce a home like environment as a commodity, Brown (2006) tells the story of recent efforts by elderly to finance and construct intentional communities that allow them to live and socialize collectively.

CHAPTER V

ALTERNATIVE MEDICINE, INDEPENDENTS, EXCHANGE AND THE ETHICS OF CARE

Introduction

In the conclusion of chapter IV I argued for a different approach to health care reform that focuses on the social conditions that allow for ethical fidelity to the caregiving process. Freedman's notion of a duty-bound ethics of care and the new Lacanian's appropriation of the Kantian criteria for the ethical act offer us similar ways of understanding how the fulfillment of duty transforms the caregiving subject. An approach to health care reform that focuses on the connection between affective intensity and ethics allows us to pose a different set of questions. Rather than the "pragmatic" considerations of the conventional health care reform debate, this alternative perspective focuses our attention on what social and economic conditions re-enforce the capacity for ethical commitment to caregiving and what social, economic, or other forces undermine it. The diverse/community economy concept allows us to specify what class and non-class conditions allow for informal caregivers to become subjects of care as well as what social conditions might undermine this commitment.

Ashley and Anasuya drew upon their family and community in important material ways in order to retain their ability to be informal caregivers. I argued that they were able to respond to their duty as free and ethical subjects precisely because they were not operating within the context of an obligate feudal relation. This is not to say that they didn't regard the care they gave as necessary (or even as something they obliged themselves to do). Rather, in different ways they felt

free to do what was necessary—even when the care they were giving was only grudgingly accepted by the person being cared for.

Ethics and Vocational Commitment

Anasuya and Ashley's gift of caregiving labor leaves us with an additional theoretical question. If the hallmark of the ethical act is that it is performed without expectation of a return, is it the "gift status" of Ashley and Anasuya's labor that makes it ethical? Are acts of professional caregivers, who are compensated for their efforts, automatically excluded from the ethical? In the next section I consider the case of three independent (self-employed) alternative care providers working in the formal market economy. Though each of these independents are compensated for their caring labor, I am going to argue that it does not follow that they are purely self-interested subjects. Rather, their livelihood functions as both the locus of the ethical dilemmas they face as they become caregivers (or perform caring labor) and as a condition of existence for their fidelity to the caregiving ethic.

Irma, Kerry, and Ruby are independent alternative caregiving practitioners. Each of these women articulates in different ways how they balance their commitment to caregiving with the need to create a livelihood that sustains them. In negotiating this challenge they have become active and complex economic subjects—engaging in conventional market transactions, reciprocal exchange, barter, gift giving, and social networking. Their complex economic behavior reflects both their ethical commitment to care and the difficulties associated with being a self-employed alternative care provider. It is precisely in this context that we can see how the involvement of each of these women in a non-capitalist, non-exploitative class process enables them to remain in fidelity with an ethic of

caregiving by providing them with the substantive freedom to control their own working conditions, to value their work, and to determine what they require to restore themselves. In making these assertions about the vocational caregiving subject, I am attempting to demonstrate how becoming an ethically engaged professional caregiver engenders a subjectivity that is thoroughly at odds with the “utility maximizing” subject of demand inducement that I described in chapter II.

Alternative Medicine and Health Care Reform: The Role of the Independent Class

Process

Irma is a thirty year old woman living in Northampton. She has been a deep tissue massage therapist for eight years. Kerry, also in her thirties, is a certified physical trainer and acupressurist who co-owns a business with her partner that provides dietary and physical fitness routines for clients. Ruby is a self-employed fifty year old Tibetan immigrant who works as a live-in personal care assistant (PCA) for geriatric patients. Each of these women may be seen to be involved in “alternative care” in different ways.⁸¹ Irma and Kerry are providing health care services that are holistic in nature. Ruby’s PCA practice is alternative in a different way. She has built up a network of referees that allows her to act as an independent contractor rather than being employed as a wage laborer. In relation

⁸¹ I recognize that “alternative medicine” encompasses a range of practices. From a western perspective some of these alternative practices have proven their efficacy (patient response was significant over placebo) in the course of treatment (acupuncture, for instance) while others have not (cranial-sacral therapy for persistent headaches) (Lundberg 2000). It may be that Lundberg as the former editor of JAMA was correct in saying that “alternative medicine” should not be thought of as the other of allopathic medicine and that, in accordance with the original mandate of the AMA, these treatments should be evaluated for their efficacy with the same scientific rigor as “western” treatments. According to Lundberg, one thing that might be said about alternative approaches to healing—especially those derived from the eastern tradition—is that they tend to be better than curative medicine at addressing chronic conditions that do not have a specific origin. For Lundberg, these approaches to healing will become truly complementary if they can become evidence-based medical practice.

to the diverse economy diagram, each of these women is involved in an independent class process, receive compensation through their self-employment, producing services that are exchanged in both the market as well as being bartered (see figure 5.1).

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
❖ <u>MARKET</u>	WAGE	CAPITALIST
ALTERNATIVE MARKET Local trading systems Underground ❖ <u>Barter</u> Co-op exchange Alternative credit	ALTERNATIVE PAID Cooperative ❖ <u>Self-employed</u> Indentured In kind	ALTERNATIVE CAPITALIST Environmental ethic Social ethic State capitalist Non-profit
NON-MARKET Household flows Gifts Gleaning Indigenous exchange Theft Government transfer	UNPAID Volunteer Housework Neighborhood Family care	NON-CAPITALIST Communal ❖ <u>Independent</u> Feudal Slave

Figure 5.1: Irma, Kerry and Ruby’s Place in the Diverse Economy

❖=Irma, Kerry and Ruby’s diverse economic activities.

Irma, Kerry, and Ruby had a lot to say about the challenges and satisfactions associated with being involved in health care as independents. Each woman was convinced that their alternative approach to health care engendered a different type of relationship with their patients. Likewise, each of them said in different ways that self-employment allowed for an approach to their livelihood that was conducive to this relationship. While Irma, Ruby and Kerry had much in common as care providers each interview seemed to bring to the fore a different aspect of care in the context of the diverse economy. Irma was the most articulate about how self-employment enabled greater freedom to control working

conditions, providing an illustration of the role that DeMartino's "productive justice" might play in reforming health care. Kerry's interview allows us to more fully comprehend how complementary medicine depends upon a different relationship between patient and provider. Lastly, Ruby emphasized how her commercial success depended upon insinuating herself into a community-based network. In explaining how this process works, Ruby's story reveals important links between the formal and informal economies. Ultimately, each of these themes emphasizes a connection between self-employment and fidelity to being/becoming an ethically-driven caregiver.

Irma

I spoke with Irma at her office in Northampton in the fall of 2001. She works out of the second story of a beautiful townhouse near the court house. Artwork adorned her waiting room, massage area and office. At the beginning of the interview I learned about how she became a deep tissue therapeutic masseuse, how her college education both convinced her that working as a nurse was "not for her" and rekindled her love for the idea of being self-employed. Initially
massage

was not a way to make a living. Not at all. It was just something that happened between friends and family and it was just, you know, shoulder rubs and scalp rubs and hand massages and foot massages and things like that. It wasn't anything other than that.
(Irma 2001, 7)

The transition from a-vocational/familial to professional masseuse was something that Irma had clearly reflected on quite a bit since it came up with some frequency in the course of the interview.

Most of her clients pay out of pocket for services. She does, on occasion, deal with insurance companies—mostly related to claims from automobile

accidents.⁸² The fact that most of her patients pay out of pocket means that payment is part of the direct face-to-face relationship she has with her patients. She seemed to feel that the financial aspect of massage was something that many people in her profession found difficult.

There's something about massage therapy, I don't know, it's the people that it attracts; I mean it's a very common conversation to have with other therapists, particularly when you are first starting out. Of course how much to charge? And then how much do you feel comfortable charging? And, you know, do you value your work at all? I think there's really a resistance to actually charging people for this work, by a lot of people. (Irma 2001)

She speculates that part of the resistance comes from the fact that this type of care resembles the nurturing care given by a mother to her child. Its status as “feminine labor”—women's work—places it outside of the market.

I mean I don't know if it's that there are so many women who are in this work. It's considered such a nurturing field so it feels strange, I think, for women to accept money for nurturing just... [indecipherable]. . . . There's that silence when someone is writing a check. And I've had to work really hard on not filling up that space with chatter, to just sort of well—let it be—while someone is writing that check. And I'm okay and I don't have to be anxious. It's weird stuff and I don't know why it is there but it is [laughs]. (Irma 2001)

What's remarkable about this comment is that Irma continues to see massage therapy as a type of nurturing/caring labor and that she recognizes that she has had to work at accepting her involvement in market exchange. She sees her urge to continue talking with her clients is in part based on a desire to maintain a sense

⁸² Insurance payments, Irma confessed, were hardly worth it because of the difficulty in getting reimbursed. At the time of the interview she was owed thousands of dollars from an insurance agent after treating someone injured in an accident. Another client had offered to pay Irma out of pocket and wait for the reimbursement herself, an arrangement that Irma reluctantly agreed to since she knew, far better than her patient, how long a wait that might be. In another anecdote related to this point, Irma told how she once exchanged legal services for massage with a lawyer, who helped her with insurance reimbursement.

of connection, an urge to, as it were, glide over this momentary intrusion of the market.

What does Irma mean here by being “comfortable with the silence” that accompanies the writing of the check—the moment where a personal and affecting relationship is replaced by a commercial one? There are, I believe, two sides to this struggle. On the one hand, it is a struggle to ascribe a value to caregiving labor in the context of a culture that sees “feminine labor” as invaluable. She speculates that this aspect is so daunting since people imagine this type of care should be free since it resembles care provided outside of the market.⁸³ This is made all the more complicated by the fact that Irma really does believe that massage work should be freely accessible since she is convinced that it is universally beneficial.⁸⁴ On the other, it is a struggle to define the value of her

⁸³ Rio (2001) describes how the transition from slave to an independent class process connects the performance of an independent class process (domestic work) to the substantive freedom of the laboring subject.

⁸⁴ There is not really one place in her interview where Irma states this concretely, rather her belief in the universal value of massage shows up partially at several points during our conversation, articulated with varying degrees of conviction. A few minutes into the interview she supplies us with a scientific explanation of the value of massage:

I would say that massage is really good for the immune system. It's a real boost to the immune system because it decreases the amount of stress we have in our body which can really be... so in that way it is really beneficial. But as far as helping people directly, you know, with say lupus or cancer—yeah, I wouldn't say it is effective other than it builds the immune system and decreases stress. (Irma 2001)

It's clear that Irma felt the need to be fairly limited in the claims that she makes here about the efficacy of massage. The question that elicited this response was fairly neutral in tone—does massage have any benefits apart from the muscular/skeletal systems? In her response Irma says that she defers to allopathic medicine in the treatment of “real” disease. The irony here is that while Irma is qualifying her response oncologists like Jerome Groopman are becoming interested in the role that stress plays in disease and the role that more hopeful states of mind might play in its treatment. It is here, precisely, that we might find the true value of complementary practices like massage. At other times, Irma is far more convinced of the universal benefits of massage:

I can talk about what I get out of body work also. There's something that really moves me about skin to skin contact. I just really love to be massaged. And I imagine that people that come to see me regularly enjoy it in the same way that I do. I get such a feeling of release and relief when I have my joints worked on, when I have my muscles worked on and I just feel sort of connected with my muscular skeletal system. It's just so wonderful to have it addressed. (Irma 2001)

labor so that she can reproduce herself as an independent (necessary labor) as well as generate sufficient surplus to meet her conditions of existence. In a sense, these are really two sides of a single dilemma. The context of her ethical-becoming, her sense of duty rests in satisfying these opposing claims of accessibility vs. the need for a livelihood. Irma's has developed a number of strategies to balance these opposed concerns.

Irma has tried a number of approaches over the years to arrive at that point where she is comfortable with people writing their check in silence, where she values her work enough to accept that it has a price. Using a sliding payment scale, frequently getting massage herself, offering her services at a reduced rate to certain customers, and accepting barter payments have all been ways that Irma has allowed herself to become comfortable with this silence. Each of these practices have allowed her to find this point of dynamic tension between her reproduction as a self-employed worker, her commitment to massage as a valuable practice of care, and her belief that it should be accessible to the people who need it.

Sliding Scales

Early in her practice Irma sold her services on a sliding scale. She saw this as a way of making sure that her services were not priced so high as to be out of reach of people who needed it but could not afford it. She said her initial efforts at implementing a sliding scale were met with confusion by her clients.

Q: It was unprecedented

Irma: There are a lot of people. . . I am very familiar with it having lived in San Francisco for awhile and up in Washington its seems as though that was done much more so than maybe it's been done

It is really in the context of these remarks that one can appreciate the different ways that Irma tries to maintain a sense of the value of her work while, at the same time, trying to make sure that people who really need her caring labor can actually receive it.

here. And there are still some people with sliding scales fees and they feel they're not gonna get rid of it. They feel comfortable with that. But, I mostly met with confusion when I would try to explain it. Cause this requires them to take a look at their finances, you know? Do quick math in their head and you know where do they fall along that range, which is uncomfortable... They would be bewildered at how I could charge, how some people could pay thirty five and others pay fifty for the exact same session. I think that it may have bothered some people that they were paying more than other people and some people felt like they had to pay me at the top end because they felt uncomfortable paying at the bottom, even if that was what they could afford. (Irma 2001)

Irma's attempt at reconciling the value that she ascribes to her labor with her commitment to making her practice accessible to those in need was in general resisted by her customers who were unaccustomed to thinking of things as having a price that was sensitive to their ability to pay. Recognizing this Irma, eventually dropped this practice in favor of a fixed fee.

Q: And the other thing that I thought about was when you change, you stopped using a sliding scale how was that, I mean how did you tell your clients? I mean did you find that everybody wanted to pay you at the lowest amount?

Irma: I mean a lot of people were just right in the middle. And I think what I did was I started out saying that a general body massage was forty-five and MT is fifty. And given that MT is what I basically did with 90 percent of my clients they'd be paying me anyways around forty-five and I just told them that I wouldn't have a sliding scale anymore and that I would have a set fee and it would be fifty dollars. I don't think that I lost anyone at that time. We were just, people were wrapped up into my practice at that point so I think some people were relieved actually. 'Cause I met a lot of resistance to the sliding scale fee. (Irma 2001)

The sliding scale seemed to be a way for Irma to become comfortable charging for her services without excluding people on the basis of their ability to pay. What is interesting is that it was the resistance of her clients to this practice that eventually led her to abandon it. While some people are resistant to thinking of "nurturing labor" as part of the market sphere, most of Irma's clients not only valued this

work, they felt like a straightforward monetary exchange for the service was easier than the difficult task of valuing the service in relation to their own financial situation.

Being a Client

Irma found it necessary to barter services with other massage therapists in order to remind herself just how valuable this work is:

I find that I, I have to get work done often, not only for my own personal health, but also as a reminder of how important the work is for me so that I feel okay about charging other people. (Irma 2001)

For Irma the benefits of massage were not simply about the treatment of chronic pain or discomfort, it was actually about having the chance to inhabit one's body pleurably, to feel relaxed and supple or, as Irma put it, simply to have someone's full attention for an hour. While Irma paid to receive body work herself on occasion, her usual practice was to barter body work with practitioner she respected.⁸⁵ This discussion of body-work exchange led to a more general discussion of the role that barter played in her professional life.

The Value of Barter

In the course of the interview Irma noted that she had bartered massage in exchange for art work that adorned her office. She spent quite a bit of time talking about her various barter arrangements with patients and this, too, was clearly part of what made her livelihood meaningful to her.

Q: So you set up the barter before you accepted the art work?

Irma: I didn't, no. I asked her to bring in a portfolio and then we took it from there. I saw her first and then she broached the subject

⁸⁵ It should be noted that there was also another way that exchanging body work with other practitioners confirmed the value of her services. Irma remarked that on occasion she received body work that was not up to her standards at all and that she had a difficult time paying for or exchanging with people whom she perceived to be offering inferior care.

with me. And she needed a lot of work, and I really wanted to work with her. And so it seemed like a really nice match. She really needed to be seen twice a week for a while. And that would have become really expensive for her. So, and then I've also bartered—someone made a weaving for me and I didn't see it beforehand. Often, someone comes in, and I know them and they need some work, they're in a lot of pain. I don't want to turn them down because they can't afford it. So I'll try to find some other way of compensation. (Irma 2001)

It has been commonplace since Marx to decry the predominance of production for exchange as an alienating force which replaces relationships between people with relationships between things. Bartering is one way of repositioning human relationships in the center of an exchange process but it also seemed to have other consequences for Irma. Irma spoke of the relative ease with which she was able to think about the value of her work in relation to other goods and services—art work, cooked meals and even legal aid.⁸⁶ This practice of barter was a way of thinking about the value of her work—the standard fee of fifty dollars—in relation to all the other goods and services that she might need from others. It is as if barter allowed her to become more comfortable with the (monetary) exchange value of her work rather than seeing the monetary value as an “alien” intrusion into the space of care.

Irma explained that while some people readily participated in barter others found it impossible—a point she illustrated with another story.

Q: I want to backtrack a little bit because I am just still interested in this question of value and money and you had said that there was this woman who had left because she couldn't put a value on her own artwork. Now, was that because she thought it was not valuable at all or invaluable?

⁸⁶ This is something that Irma shares in common with many other categories of self-employed workers. For instance the building trades are famous for engaging in commercial barter. Trading plumbing for electrical work when building one another's homes has the added advantage of being essentially untaxed income for both parties involved in the exchange.

Irma: Oh no, I think it's because she didn't see it as having any value at all. She was uncomfortable with making that decision. I mean, I would have been happy with anything, I didn't really feel as though it needed to be an equal.... it didn't need to be fifty dollar's worth of whatever, it just had to be kind of what a session's worth of body work is to them. And I leave it up to them, you know, to make their decision. And it was really difficult for her. And she was just made so uncomfortable by it that she decided not to pursue it. (Irma 2001)

Relating this story allowed Irma to reflect more closely on how she has ultimately come to see the value of her work and to reconcile herself with producing it as a service for exchange in the market. In a sense Irma is able to engage in these barter relationships precisely because she does know the value of her labor.

Being Independent: Ethics and Non-exploitation

Irma was quite aware being self-employed enabled her to engage in non-monetary exchange as well allowing her to be flexible about the price of her services. This sense of flexibility that comes from being her own boss has other important implications as well. Irma explained that the longevity of a massage practice is a general concern because of the amount of strain that it places on the hand tendons of the masseuse. Irma takes full advantage of the flexibility of self-employment by taking five weeks to two months off every year. What she loses in terms of clients and yearly revenue is more than made up for, in her mind, because her lifestyle more closely approximates that of Europeans and because it might lengthen her practice by several years.

This same line of thinking has prompted her to think about her practice in a different way. Irma has over the years developed a network of massage therapists, reasoning that if she can create a mutual aid relationship amongst these practitioners they all could take one another's clients in exchange for time off. This set of relationships might afford other possibilities as well. Irma and her

partner wish to have or adopt children. Creating a mutual aid network might not only allow her to keep her practice while getting time off to have children, it also might allow members to provide childcare on a rotational basis.

Self-employment created the conditions that enabled her to become comfortable with accepting monetary compensation for her caregiving labor. Barter, flexibility with respect to her compensation, and engaging with other practitioners is, in turn what allows her to consider the work that she does both valuable and meaningful. It is this same sense of freedom that allows her to attend to her self-care as well as the pursuit of other possibilities.

One got the impression from listening to Irma that this process of professionalization *en toto* amounted to a sort of traversal of fantasy. Žižek (1991) describes the traversal of fantasy as the process of shifting perspectives such that what once appeared to be an impassable contradiction or a site of traumatic impossibility becomes simply another point on the horizon.⁸⁷ The commodification of “nurturing labor” and its “invaluable” nature formed a sort of symptomatic knot in Irma’s identity. On the one hand she truly believes in the central importance of affecting touch and on the other, she, along with many other body-work professionals, had a difficult time charging for their services, convincing themselves of the value of this work. This is commodity fetishism experienced from the perspective of the anxious producer—“just what is my work worth in exchange, how can it enter into a relation among things?” Barter acclimatized Irma to production of service for exchange by de-fetishizing the exchange process.

⁸⁷ Usually the “traversal of fantasy” is thought of as “the end of analysis” in which the analysand is able to see a formative trauma as simply an ordinary event.

Through barter she was able to see that “nurturing labor” was commensurate with legal services, art work, building materials, and home care. The end of this process was, for Irma, to regard monetary exchanges as simply another particularly convenient type of barter. The monetary value of her work at that point ceases to function as the “thing”—the symptom—and becomes an ordinary object in a chain of equivalence.

Kerry

I interviewed Kerry late in 2004 in her home which she built with her partner and the help of twenty or so friends just outside of Amherst, Massachusetts. After graduating from college, Kerry became interested in health care partly because she suffered from chronic illness herself:

I always felt fairly healthy before college. But I was living in a lot of really cold living situations in college and didn't really have a lot of money to feed myself really well and I was trying to do the politically correct diet thing and I wasn't really eating red meat because I was trying to not eat meat for all kinds of ethical and social reasons. So I didn't feel strong. So someone suggested to me that acupressure was a fairly quick thing to get involved with and it seemed really interesting to me.⁸⁸ It didn't seem, and I don't mean to say anything bad about massage but massage seemed really boring and I thought I would lose interest with that very quickly. But the acupressure is like med school, it's learning traditional Chinese medicine. A lifetime of study. And that seemed really interesting to me and I really loved my teacher. (Kerry 2004)⁸⁹

Kerry completed her training as an acupressurist in 1997 and intended to establish herself as a self-employed independent practitioner. In retrospect, Kerry

⁸⁸ Acupressure, like the more familiar acupuncture, is a non-allopathic approach to healing. The basic idea is that there are energetic meridians which run throughout the body connecting various groups organs and nerves. By manipulating points along these meridians one can promote the health of the associated organs.

⁸⁹ Kerry also had a dimmer view of her commitment to alternative medicine—that she lacked the drive necessary for medical school and that she was so desperate for money after graduating from college that she chose a career path that seemed to require the least amount of training.

realizes that while she went to school with a wonderful teacher who had a grasp of acupressure, a successful practice and school, he did not spend a lot of time teaching his students how to run their own independent businesses. In reflecting on it, Kerry also realized that she had a naïve expectation that running an independent business sort of magically works itself out—a expectation she was certain she shared with many of her classmates.

Our last class period (teacher's name) tried to talk to us about how to build a business. And I had been, you know, trying not to think about this all along and I used to think how great it would be when I had this flourishing practice and all of these people coming to me and then I sort of really, realized right away well "who are these people? Where are they going to come from and how are they going to know about me?" This is not my strong point. And this is like many body workers, I could just look around the room and say to myself—I mean, who is going to come to these other people? I mean if you are not innately ready to market yourself, or ready to learn how, or ready to hire someone else to do it for you, then where the hell are these people going to come from? And it turns out that they really don't just materialize and you really have to put quite a bit into it. And people used to say "well you just have to put it out into the universe and they will come!" (Kerry 2004)

At this time Kerry was also partner in a publishing business with her partner that provided lecture notes to students at the University of Massachusetts. This business was generating a significant income for her and her partner and she was partially able to content herself with the idea that acupressure has an intrinsic value whether or not it became her vocation.

And I started to say to myself, and now I am not sure if it was due to insecurity about starting an acupressure business, but really, I would say to myself, well, most of my time is taken up with this other business so if I end up not doing the acupressure, at least I have learned these valuable skills for my friends and family. It's like training for motherhood. Right, I have learned all of these alternative care protocols and I feel really confident about doing body work on friends and families and children. And so then I thought, "that's great no pressure" and then I assumed it would just take off. (Kerry 2004)

Kerry, like Irma, went through a process both of convincing herself that the skill she learned had a value that other people could recognize and that this value corresponded with a price for her services that would enable her to make a living. Kerry spoke at length about the circuitous route she has taken to becoming a professional alternative care provider—one that led her on a different path than the one followed by Irma. When Kerry became convinced that clients weren't going to simply materialize she joined an already existing alternative medical practice as an hourly employee.

Capitalist Detour

Kerry eventually allied herself with an established chiropractor operating in a neighboring town. The chiropractor was able to accept insurance for his work and this put him in a position to pay Kerry for her time. Though the compensation was relatively low, Kerry figured that this would be a good way to build up a customer base. In addition her employer offered to teach her elements of his eclectic healing practice. Initially this arrangement worked well. The chiropractor could book several clients at once, rotating amongst them while Kerry provided complementary care to the patients he wasn't seeing at that moment. This was not simply an exercise in clients milling. According to Kerry, it was also a way to make chiropractic work more effective:

I was working with the doctor hand in hand, in that I was sort of the warm up act or the post adjustment person. One way or another I was there to help the person's muscles either be ready for the adjustment or hold the adjustment because it's the muscles that are pulling the bones out of whack. Unless it's a traumatic hit that you take in an accident, it's your muscles that are holding your bones in place or out of place. So, I would go in and do soft tissue work in order to facilitate the doctor's process. So I was making ten dollars an hour without benefits for doing that. We had a terrible, poverty-minded no good business woman running all of the finances of that business. And she, I probably should have looked into this more

myself, but she claimed that the doctor could not bill for my services. That may be true but there may have been another way around it. (Kerry 2004)

Kerry's statement acknowledges both the value of her work to the practice and her formal existence as an exploited wage employee.⁹⁰ After several years there, Kerry's pay remained ten dollars an hour which became increasingly hard to take when she considered that she was charging her private clients considerably more than that and that the chiropractor had failed to hold up his end of the bargain to continue her education.

These things placed a strain on the relationship but it was actually something else which ended it. In addition to sharing clients, she and the chiropractor would exchange services with one another and they also agreed to treat one another's partners. Kerry felt that while she did consistent and conscientious work for the chiropractor and his wife, he failed to reciprocate this in kind, treating both Kerry and her partner with an uncharacteristic brusqueness. It was really this asymmetry that acted as a flash point that brought things to a head.⁹¹

Kerry confronted her employer, saying that she did not feel that she was getting paid what she was worth and asked that her hourly rate be immediately

⁹⁰ Of course, even if Kerry were making twice her hourly rate she would still be an exploited participant in a capitalist class process though the rate of exploitation would be lower assuming her productivity level remained constant. If her employer had been more open minded another possible resolution to this problem could have been transitioning to a two person communal class process.

⁹¹ It is interesting to consider the contradictory role that non-monetary, bartered exchange plays in both the stories of Irma and Kerry. For Irma, barter exchange seemed to be a source of richness and possibility—from beautifying her work environment to creating possibilities in her life for leisure or even starting a family. Barter plays almost the opposite role in Kerry's relationship with her employer. Rather than cementing a bond between herself and her chiropractor employer, it served to highlight the distance between the social character of their working relationship and the

doubled. She not only felt justified in asking for twenty dollars an hour, she also had enough of a sense of the overall finances of the business that she knew they could afford it:

I know that it was fifty dollars to basically see him. And he could see three to four clients in an hour. And with me there he could fit in a few more. And you know, eight times twenty is one hundred and sixty. I mean its not that much money. One hundred and sixty dollars pays for my being there. That is basically three more clients. It's so worth it because the patients seem to love me. I don't know, it's hard to know from my perspective but it was nothing but smiles. And the doctor would come in and they would say "go away, don't take her away." So many people would say that. And Dr. Bob and I worked really well together and we had a little comedy going on together. And it was fun and people felt a lot of times like they came to the office, and its hard to say this about yourself, but I sort of felt like they saw Dr. Bob and I as these cool fun-loving happening people. It was sort of like they came to hang out with us. It was almost like a rent-a-friend situation. Plus we were healing them. It seemed like such a nice dynamic. And I know he liked me and I liked him too so the financing just needed to work out but, I was countered. The counter offer was twelve fifty an hour. And I was so insulted and I immediately said "I can't do this anymore" so thanks so much. And he said "well, when do you want to stop?" And I said I wasn't on the schedule and I said I think I will just not come in. (Kerry 2004)⁹²

Interestingly, in her final weeks of working there several of the clients told her upon learning that she was leaving that she was the reason they came to the chiropractor in the first place and they were interested in being her client after she left. Kerry continued seeing them for several weeks in the chiropractor's office, an arrangement which brought certain other dimensions of her working relationship with her former employer to light:

Kerry: At that time I was doing four to six private hour sessions a week. And these people were able to bill through insurance because

formal existence of capitalist exploitation. For Kerry it was not the low wages that ultimately ended the relationship but the lack of courtesy in their barter practice that was the final straw.

⁹² "Dr. Bob" is a pseudonym that Kerry and I used when discussing her former employer's practice. Kerry still respects her former employers work and she asked me to conceal his identity—a desire that in so ways reflects her continued ambivalence about her experiences working with him.

I was affiliated with the chiropractic office. For some reason when people would come in for an hour session with me they were able to bill through the chiropractic insurance and I am kind of forgetting why now. (Laughs).

Stephen: Was this some kind of slight of hand or is this what makes you suspect that maybe you weren't being told the entire truth about reimbursement rates (what they could be reimbursed for?)

Kerry: I just think that it's possible that there was some laziness going on. The receptionist slash office manager was recently let go because she wasn't really working and I think that was going on when I was there and I was slightly hip to it but not to the level that it was going on. And I think that she could have probably found a way around it. I think a smart, savvy office manager could have found a better way to pay for my work and I think that she didn't do it. That's my opinion. So anyway you can keep seeing people. Prior to this I wasn't paying for office rental. So if I was seeing a client normally I was seeing them there in the office. If I was seeing a client they didn't make me pay anything for that hour session but now it became: "okay, well if you are not working here the standard fee is twenty dollars an hour to use the room."

Stephen: Kind of ironic, isn't it? (Kerry 2004)

While many people shared this high opinion of Kerry's services, only one client was able to continue to pay out of pocket for her services once she left the office and was no longer in a position to be reimbursed through insurance. While Kerry could see that some people were not in a position to afford her services, she also suspected that this was an expression of a resistance that people have to paying for caring labor:

They are very much in the mindset that if my health insurance isn't going to pay for it, I am not going to do it. It's really unfortunate that people are just so stuck in the mindset that anything that I do for my health should be paid for. You know I am paying for health insurance or my job is paying for it for me but that otherwise would be money that I would get in my paycheck if they weren't so that's my, that's being paid into that so I am going to be connected to that, for my health. (Kerry 2004)

With this explanation, Kerry turns the conventional wisdom about moral hazard on its head. Kerry argues that third party payers distort people's thinking about their

own well-being and lead them to undervalue (and under-consume) services that are not covered by insurance plans.⁹³ At this time, Kerry began to think more deeply on the way that people value their health and the kinds of services that they consume. While she could see that Dr. Bob was different from other chiropractors—thinking holistically rather than billing by the adjustment—there was also a limit inherent in his approach to people’s well-being:

Kerry: So here we have what would be pretty much a best case scenario for an injured person going to a chiropractor and he is spending a lot of time with his clients. He's this great guy, he is healing a lot of people. But these were people who were pretty fit, people like you who were fit but your knees were bothering you. But your knees are going to keep bothering you until you get fit and strong. If your IT bands are made out of steel, it doesn't matter how much you go to Dr. Bob, it will only get better if that tissue becomes more supple. So I started thinking that I would really like to be able to give people homework to get them out of the pattern that they are in that is getting them in here in the first place. (Kerry 2004)

As much as Kerry admired Dr. Bob’s practice, she felt that chiropractic work was still curative medicine, an attempt at dealing with bodily trauma after it occurs.

⁹³ Kerry had a particularly complex assessment of this type of moral hazard that also highlighted the role that gender socialization and social class might play in leading people to undervalue services that actually promoted health (rather than simply treating injury or illness):

Kerry: Some people, I noticed a lot for example some of the guys that I used to work with at an office at UMass would have nothing to do with massage or acupuncture. They didn't go for that touchy feely stuff; they didn't want to be touched. They really didn't want to be touched.

Stephen: Some people denigrate this health care because it is too intimate and too invasive.

Kerry: Mhmmm. These are people who are probably fairly homophobic and would never go to a nude beach, probably. I mean these are people who are freaked out by the body.

Stephen: sort of a male version of a prude.

While Kerry acknowledged the role that fear of intimacy and the body played in people’s resistance to this type of work she also saw that some people more readily embraced it than others. Kerry argued quite simply that part of the reason why clients that paid for her services out of pocket kept coming to her was because they had learned to value themselves and her health.

After she left his office she became more interested in pursuing alternative care practices that promoted or produced well-being.

The Production of Health: A New Business

It was around this time that she and her partner, who had always been avid cyclists, became interested more generally in health and fitness as well. They enrolled in a course taught by Paul Chek, a personal trainer and nutrition coach. Their interest in Paul's work had as much to do with their commitment to their own well-being as it did with developing a training and nutrition practice. Chek training starts with the principle that core strength and the physical alignment of the body are the basis for a body both free of injury and capable of athletic prowess.

Chek training is very different from the training Kerry received as an acupressurist. The focus there was centered on the healing virtues of integrative (non-allopathic) medicine. The commercial viability of a practice was not something that was discussed until the last week of the training period. In contrast, Chek trainers discussed how to build a commercially successful business by inculcating the belief that what one could teach a client was of immense value to their health and well-being:

Stephen: So they were a bit more savvy than the acupressure teacher about the business end of it?

Kery: Oh, yeah. They have told us from day one that you have to charge to what you need to live, because we need you out there doing this work. And if you can't make a living doing this work then you really need to start taking a look at a poverty mindset that you might be holding from youth because it's insane if you can't make money on this. And they are shining examples of business success

This caused Kerry considerable distress since she, like Irma, really believed that everyone—from artists to working class people in manufacturing—could benefit from body work.

and they have a forum that you can consult, and the business end is a hot topic. (Kerry 2004)

This training addressed directly the sense of doubt that surrounded Kerry as an alternative practitioner by giving her a way of conceptualizing the value of the service that she and her partner are offering. Kerry came to see that part of her job as a physical trainer/nutrition coach was to get people to value their own health:

In general now, I am convinced that being healthy is about doing a lot of work. Taking charge of your own health completely and not expecting that a professional is going to do it for you. And no matter who you are going to see, whether it's a chiropractor, a gastroenterologist, your personal trainer, your acupressurist, if you don't realize that actually you're the one that is in control of this and these people are going to give you what they have and what they know of, they are going to share what they know and coach you in what they are trained to do. But you're ultimately in charge and until you realize it you aren't ever going to get healthy or, if you do, it will be a fluke. But this is the truth of health. (Kerry 2004).

Kerry and her partner made arrangements to have office space in a local high-end gym. They used their hard won carpentry skills to build an office for themselves within the gym where they could do private assessments. In exchange for space they agreed to run the gym's exercise orientation program.⁹⁴ The hope is that people who come to them to learn how to use exercise machines will, upon hearing about their services, want to work with Kerry and her partner as well. The initial assessment, development of a fitness and nutrition program, and follow up sessions cost typically six hundred dollars per client. Both Kerry and her partner related that many people become reluctant to continue with training once

⁹⁴ Having been one of their guinea pigs I can attest to the extensiveness of this assessment. One of the things that is, I believe, unique about the Chek approach is that his trainers look at how you carry your body for asymmetries in muscular development and flexibility. The first goal of the trainer is to correct these imbalances in the body lest they lead to repetitive stress injury. Considering that sports related and repetitive stress injuries represent a huge portion of health care spending—from youth to the baby boom generation—this approach to fitness, if widely adopted, could be seen as a major innovation in preventative health care.

they learn of the cost. It is ironic that many of these same people would readily justify a similar expenditure on a home gym or readily receive very expensive services that correct damage to their body caused by improper use of their body. She seems to be asking why is it that people cannot seem to value a fit, injury free body?⁹⁵

Kerry began this interview by questioning the value of alternative medicine and connecting this to the way that she questioned and doubted her self. By the end of the interview, when Kerry was talking about her current work, it was if her entire persona had shifted and this is reflected in her concluding assertion:

Generally, I just do not feel that western medical doctors have got the whole picture. I am tooting my own horn and it feels a little weird to say this but I think I do. I think I know who to refer everyone to. I don't think I have all the answers but I know how to write a damn good exercise program that is going to get their body in really great shape. And I know that you got to go to this person to get checked for parasites and that person to see if your adrenals are functioning and you should go to this guy for an exercise because, you know, your arm, your shoulder is not responding to this and that we are doing and we have to make sure that you are not torn (Kerry 2004).

Kerry's sense of having a masterful and important view of bodily well-being is quite a different self-conception than that of the person who accommodated themselves to exploitation in the chiropractic office.

⁹⁵ It seems that there might be several answers to that question. Young people who are fit tend to be incapable of imagining what it is like to be fundamentally damaged—to have for example bad knees and a bad back. In contrast, people who are in their thirties and forties seem equally ready to accept that the loss of bodily function is simply a matter of age. The difficult thing here is that that is undeniably true. The question from an alternative care perspective becomes how to distinguish “aging” from preventable/correctable abuse of the body. For instance, is it just a matter of age that one cannot touch their toes or lift twenty five pounds? Answers to these questions are individual, of course, but that is precisely why health and well-being are best thought of as substantive freedoms we must cultivate within particular limits.

Health as an Empty Signifier

Irma's story focused our attention on how she, as an independent alternative health care practitioner, taught herself how to place a monetary value on her caring labor. By valuing the service she provided, being able to translate that value into monetary and non-monetary types of exchanges, she was able to arrive at a value of labor power that reproduced herself. Kerry's story began in a similar way—she could see the value of integrative medicine but she did not know where to begin to make it an actual livelihood for herself. This disbelief partially stemmed from her lack of confidence but, more importantly, from her recognition that this work is not valued in society. Her experience as a wage employee gradually convinced her that it really was the attitude of her clients that needed to change. Kerry became convinced that her clients needed to “take responsibility” for their health just as she came to realize that she needed to take responsibility for her working life. Kerry's experience suggests a link between the non-exploitative class process she participates in and this different way of valuing health.

The success of alternative medical practices like Kerry's actually depend upon engendering a new set of practices, desires and self-understanding in relation to total well-being. Rather than simply reflecting the “preferences” of consumer clients, as pro-market reformers like Herzlinger would have it, Kerry's holistic practice revolves around a process of resubjectivation that deliberately aims at creating a new understanding of health. The biggest challenge in this process of resubjectivation is to convince the patient that they are not the passive recipient of medical services but an active agent in the production of their own well-being. Thus, Kerry's task is not only to undo the cultural expectation that

regards only services that are acceptable to insurers as valuable, but also to resist the passiveness that this attitude engenders. Once more we are confronted with another form of commodity fetishism in which the patient mistakenly believes that they can simply buy health. Such an idea excludes the possibility that we can work towards and value well-being with the assistance of others and that it might be worth paying for.

These allied difficulties—“commodified health” and the passiveness—pose a unique challenge to Kerry as an ethically-driven care provider. Like Irma, she isn’t simply an advocate for well-being—she has dedicated herself to her own well-being to model the healthy body that she is trying to convince others to value. Far from being a source of shame, or something that is reluctantly engaged in, the commercial exchange of her professional services constitutes for Kerry a form of validation. The question from our perspective is to what extent does Kerry’s involvement in a non-exploitative class process facilitate this revaluation? Being the first receiver of the wealth she produces and establishing for herself the distinction between necessary and surplus labor she is constituted as the subject of an independent class process. There is a confidence that separates Kerry-as-independent from Kerry as exploited subject of the capitalist class process. The subjectivity that this non-exploitative class process partially engenders, this sense of mastery, is what allows her to regard herself as a capable person, one who can inspire this sense of capacity in her clients as well.⁹⁶

⁹⁶ I can readily imagine objections to both the substantive claims that Kerry makes about her approach to personal training and the intensely normative notion of “self-improvement” that Glyn Daly (1999) refers to as “California Protestantism” that is really little more than a thinly disguised narcissism. Indeed that may be part of what motivates Kerry’s clients to come and work with her. On the other hand, it is also possible that this approach to health care might offer hope to people with systemic body issues that confound “western medicine” through its focus on diet. Likewise,

Ruby

I interviewed Ruby in her home in Hadley in late December 2004, during a brief respite from a truly cold and snowy Winter. Ruby is a Tibetan refugee who moved to this country about ten years ago. Ruby is a self-employed personal care assistant with a relatively unique financial relationship with her clients. She had a lot to say about how she developed this relationship but her background story, how she came to the United States after fleeing Tibet, was what she seemed to talk about with little prompting and, to be frank, it was so fascinating that I was reluctant, at first, to steer the conversation back to her present occupation. In retrospect, this narrativization of her journey here also seemed to have important implications for Ruby in terms of how she understood the ethics of her professional caregiving practice. As with Irma, much of this revolved around the question of how much to charge. Like Kerry she was similarly concerned with what it means to provide this service and she was very clear that her professional standards were higher than those that governed the industry of which she is a part.

The Journey Here

Ruby, along with her family, fled Tibet when she was a small child. Her memory failed her here but she believed that she was about eight years old. The story of this flight was truly amazing tale. No one in her village had traveled from their mountain homes to their eventual destination of Nepal and then India and, in hearing the tale, it's remarkable that anyone made it, let alone Ruby who was eight

given the meteoric rise in spending on sports-related injuries any approach to physical training that emphasizes mobility and suppleness in addition to strength is a frugal investment in preventative medicine.

years old at the time of her exodus. When she arrived in India she was taken in by a Catholic mission and raised there.

Eventually, and in spite of her poor health, she was admitted to nursing school and trained there. She eventually worked in a hospital run by the same order of nuns that had raised her for a number of years. It was there that she learned from other Tibetan immigrants that her sister was also alive and that she was the young “bride” of an Indian man in the South. Ruby was able to save money from her small monthly salary and, after seeing her sister’s sorry state, she began to remit money to her, eventually buying her sister’s freedom.

The need for money drove Ruby from India, first to the Middle East—to Dubai and Saudi Arabia—before she came to the United States and settled in the Pioneer Valley. She worked at the Franklin County Medical center as an aide and was able to buy a home in Hadley. She eventually found that the expense and time of traveling to and from work made this job a poor fit. She began working at a local grocery store, Bread and Circus, that caters to consumers of organic food. Ruby has a friendly and solicitous manner so it was no surprise to me to learn that she rapidly became friends with her coworkers as well as many of the regular customers who sought her out to consult on personal matters during her breaks.⁹⁷

⁹⁷ Ruby said that her job at the organic food store—as one of the “deli girls”—constantly put her in contact with the customers:

So, anyway, but over there all the business is food and talk to the customer. The customer would come in and say “Oh, I am very depressed today.” And I would take my break and talk to them and they would say “oh, you healed me!” and this and that. I would say “No, I am not healing you but I am just encouraging you that nothing is permanent. Think about it. Nothing is permanent.” (Ruby 2004)

In the interview she readily recognized that many of her customers, largely white upper middle class Americans readily imagined her to have some “mystical insight.” She laughed to think of it and said that any insight she has come from the relatively hard life that she had led. Nevertheless one could also see that her patience and willingness to listen were exactly the qualities that caused people to seek her out.

Alternative Care in the Web of Social Relations

It was precisely the creation of this extended social network that she developed at Bread and Circus that allowed her to develop her unique PCA business.

I learned from a friend that his father was sick from a stroke and he said “Ruby you would be perfect!” Because all of the customers loved me at Bread and Circus. Because I worked hard and was nice. (Ruby 2004)

Ruby laughed to think that she had just gotten to the top of the pay scale at Bread and Circus (\$13/hr) only to quit in order to become a personal care assistant (PCA). A local elder care coordination service, Highland Valley, learned about Ruby by reputation and began recommending her to other people in the area. Eventually Ruby had enough clients for a full day’s work—mornings with someone in Amherst and afternoons and evenings with other clients elsewhere. This schedule constantly kept her traveling throughout the Valley. Ruby’s experience speaks to the important connection between social networks and informal employment that the diverse/community economy and the social economy attempt to represent theoretically (Gibson-Graham 2006, Leyshon and Lee 2003). In my view, this relational dimension has not only been the cause of her provisional success as an independent PCA, it also is part of the reason why she is able to line up her vocational commitments with a particular sense of ethical duty.

Most PCAs are hourly employees that work for a capitalist employer. As I learned from another interviewee, Cindy, who was at one time the proprietor of a care assessment and coordination business, the going rate for these employees is around eight dollars an hour for work that can be dirty, occasionally involves heavy lifting and is, almost always, emotionally taxing. According to Cindy the

unsurprising result of this arrangement is that PCA workers feel little loyalty or commitment to their job.⁹⁸ In contrast, Ruby was obtaining work through a social network that formed around her as an independent employee. Her status as self-employed enabled her to do a number of things including setting her own rate of pay. When I asked Ruby about how much she charged she explained:

Usually we have the C.N.A rate, fifteen dollars an hour. It's a standard fee. But if somebody said "my mom does not have that much money" then I try to accept twelve dollars. Fourteen, twelve, whatever. Or if I say okay, you hire me for the whole day, 12 hours or whatever, give me just \$100 (Ruby 2004).

Ruby's involvement in an independent class process allows her to place a value on the services that she provides. She seems to justify her higher wage because she sees herself as a certified nurse's assistant (CNA).⁹⁹

Ruby's practice of charging a variable rate for her services highlights the Marxian distinction between necessary and surplus labor that I discussed in the conclusion of chapter IV. 1(2002) define necessary labor as that portion of the total product that secures the material conditions for the reproduction of the person engaged in the fundamental class process. The definition of "necessary labor" is determined by a set of social conditions—the law and morality of particular cultures, expectations regarding consumption, the social distribution of power, race, gender can all play a role in determining the value of labor power. The "surplus" is that portion of the total product produced by workers beyond what is

⁹⁸ Of course, it is important to keep in mind that agencies that are billing for their PCA employees collect considerably more than they pay out to their employees in wages and frequently double what they pay their employees. From a Marxian perspective then, the rate of exploitation for PCAs working in the capitalist sector approaches one hundred percent.

⁹⁹ Ruby considered herself a C.N.A even though her training that she received in India was not recognized in the United States. This is a curious fact since there are other professions in the health care field where certification is far more portable.

necessary for their own reproduction. In the case of exploited capitalist employees—such as the PCAs employed through temp agencies—the surplus is the difference between the hourly rates the temp agency charges for the PCA’s services and what the temp agency pays out as a wage to that person.

Things get more complicated when one considers that Ruby herself is partially determining the difference between what is necessary for her own social reproduction and what is the surplus portion of her compensation. It could be that her own narrative gives us a sense of what this difference is for her. The standard rate for her is \$15 an hour, essentially double what a PCA typically makes. She is willing to negotiate the price if her client is unable to pay the standard rate—“Fourteen, twelve whatever”—which one could see as returning some portion of the surplus back to her client as a gift. This might suggest to us that she sets the difference between necessary and surplus labor at \$3 dollars per hour (or a rate of non-exploitation of 20 percent—only 20 percent of the value she is capturing is surplus value).

She also said that she is willing to accept \$100 dollars for twelve hours worth of work if she is paid for the whole day. One way to interpret this remark is that not having to travel allows her to reduce that portion of the total product that is necessary for her reproduction as a PCA. This makes sense because she does not have to drive as much or spend as much money on fuel in order to do her work. On the other hand, \$100 for twelve hours of work expresses itself in an hourly rate of nearly \$8.30 an hour, less than what the typical PCA is paid in the capitalist sector. It could be that for Ruby—a Tibetan exile—places the actual

value of her labor power at \$8 and the rate of non-exploitation, when she collects her full fee, is actually closer to 100 percent (Safri 2005).¹⁰⁰

One way to see this is that Ruby's considerable flexibility in terms of what she is willing to charge for her services gives her a competitive advantage when she is competing with services offered by a conventional capitalist employer. The other way to see it is that Ruby actually is a generous person capable giving all of the surplus value she could capture back to the client if they are willing to take her on as the sole care attendant.

During the previous year, Ruby had the opportunity to be a live-in PCA for "Mary," an eighty-eight-year-old woman.¹⁰¹ She had been referred to this woman's family by Highland Valley Elder Services in the fall. Mary had two sons, one who lived in Virginia and another who was a college professor at Amherst College and a daughter who lived in New Jersey. All of them had an interest in keeping their mother out of a nursing home and so the arrangement was that she would go between the homes of her two sons. PCA help was hired using Mary's savings and inheritance.

Originally Ruby was hired for the six months that the mother was in Amherst. She was informed when it came time for her charge to return to Virginia that she should begin looking for other work. At the time Ruby was working two

¹⁰⁰ Maliha Safri's (2005) work on the relationship between immigrant communities, the price of labor power and the culturally constructed notion of the value of labor power is quite instructive here. She argues that it is precisely cultural notions of the value of labor power that allows immigrants to the United States to reproduce their labor power (at a much lower standard of living) while setting aside the "extra money" to start a business or to remit home, etc.

¹⁰¹ Ruby asked me not to use the woman's real name so a pseudonym has been provided.

shifts with Mary because one of the other PCAs had recently quit. Rather than look for other work Ruby decided to make the two brothers an offer

I said “Why not we settle the price and I will travel with you?” And they said “Really Ruby? We don’t want to lose you! You are so sweet!” But I said there are a lot of jobs. Jobs are there, but I like to stick with one person for a long time. So, you will know me more and your mother will know me more. If your mother keeps changing the employees and nurses she will get agitated. They (older people) get annoyed . . . their mind is like a children, you know? (Ruby 2004).

Ruby is willing to forgo some or all of the surplus value she might capture as an independent in order to provide constancy to the people in her care. When she is able to capture surplus value she saves, continues to remit income, and invest in real estate.¹⁰² While thrift is clearly something that one can practice when one has a low valuation of necessary labor, Ruby says her flexibility with respect to the surplus is an effect of her ethical commitment to providing geriatric care as well as her personal and spiritual convictions

PCA job is very challenging. For me I was taking care of Mary as if she were my own grandma because I never got a chance to take care of my mom, my father, my grandpa, anybody. So anytime, first of all in my country when we take care of the elderly it is called dharma. A good deed. Secondly we respect them very much and after so many years we feel they are like a children. You know sometimes they laugh, sometimes they cry, sometimes they talk to you, sometimes they will abuse you, sometimes they will beat you up. (Ruby 2004)

At first blush Ruby’s comparison between care for the elderly and care for children might appear to be an affront to the dignity of the former. When I asked

¹⁰² Evidence abounded for other uses of the money that she considered above the rate she considers necessary for her personal reproduction. She owned a two story house in Hadley in which she also had tenants. While I was interviewing her she was industriously working on semi-precious bead necklaces which she sells around the holidays to local college students. She continues to remit money to relatives in India. She also has relations in Tibet who are desperately poor but it is unfortunately impossible to send money to them.

Ruby about that she insisted that when you are taking care of elders who are suffering from dementia this is not so much an unfair analogy as it is a felt reality that demands considerable patience. Ruby sees this sense of patience as something that she has tried to cultivate in herself but for her patience is only a first step. Effective PCA work, in her view, means making friends with the person that you are caring for.

I tell them that I am their friend. I tell them to help themselves but if they need a little help just give me a holler and I will give them help. I just keep everything there and keep everything ready and sometimes we don't have to feed them. And they will say "Oh you are my friend! You are so sweet, darling, thank you. Are you going to eat with me?" And then I will eat with them. Then they will eat and talk and calm down and everything. But sometimes I have seen people like this. And I see other people say "Okay (slams down cup) there's your food! There's your drink. Okay, there's your napkin. Okay, eat now!" And then they go to the kitchen. I don't do that. Yeah, I do my responsibility. I do my duty, their priorities come first. Very well, keep clean and company and if they want to take a nap, take nap. Like I said before, these are all necessary steps to be done so this is first priority. (Ruby 2004)

Ruby recognizes the difference between herself and other PCAs in terms of her willingness to identify with her patients, even befriending them as a part of the duty of being a caregiver. This, of course, is not in the job description of a PCA but her willingness to do it is precisely what makes her such an effective caregiver. This leaves us with an intriguing question—could it be that Ruby's involvement in an independent class process not only allows her to determine the value of her own work but also to redefine the meaning of quality care?

In listening to Ruby, one could make the case that it is partially her self-interest that motivates her to work so closely with her patients, to be attentive to their mood. According to Ruby, mood swings and violent outbursts of patients are a major challenge in PCA work. While the PCA worker who does not identify

with their patients might see the moodiness of a patient suffering from dementia as their permanent or “natural state,” Ruby has developed a specific practice that has enabled her to change the “mood” of her patient through forms of direct engagement:

You can change their mood. But that all depends upon the PCA. I try to change their mood. I have had not very hard time. Most of them are very sweet. Only one lady was very... in the night she don't sleep but she walk with a walker [imitating loud noise]. In the daytime she sleep. Loud, yeah. So then she gets very irritated in the night. So I started walking with her and making coffee and staying up and telling stories . . . Elderly definitely yes, they are my friends. Nobody hates me, nobody hit me. Only somebody has dementia they will hit you and say “I want to get out of my house! This is not my house!” And I say “Grace, this is your house. This is your son's picture, this is your cat, etc.” And they will say “No, this is not my house, I never saw that picture before.” And during that time, they have dementia. So you have to follow them, whatever they are doing. Let them walk around but shoulder to shoulder, I don't want them to fall down. I don't want them to fall down and after a few minutes they'll change their mind. Dementia does not stay long. (Ruby 2004)

I asked Ruby if her previously stated belief in the impermanence of all things is part of what allows her to adopt this particular attitude towards her elderly patients who suffer from dementia. Ruby responded with another story where she got an agitated patient of hers to teach her a Christmas song. The patient, who couldn't believe that Ruby didn't know any Christmas songs, began to teach one. The point Ruby seemed to emphasize was that the manifestations of dementia are, for the most part, impermanent, and that engaging with the patient is one way of allowing the dementia to pass without incident. The question from our perspective is, how is Ruby's approach to patient care enabled and sustained by the rate of remuneration and relative freedom that she enjoys in an independent class process?

One can easily see how Ruby's approach here depends upon her engaged and inventive nature. A less motivated or committed individual might withdraw from a demented patient, refuse to (re)engage them or simply sedate them. This could only have the effect of making the sense of disorientation/alienation more pronounced as the patient would be treated more like an object to be handled than a person to be respected.¹⁰³ When working with others, Ruby tried to impart this insight by appealing to the self-interest of other PCAs working on the same charge. She would explain to them that really engaging with the patient not only helps them, it makes the work easier. She also told me that she confronts other PCAs when she feels that the work they were doing are not up to her standards both because it makes her job more difficult or because it compromises the health or insults the dignity of the patient in their care. Ruby gave me the impression of not wanting to gossip about other people and so she dropped the subject. What she did say though gives us another sense of the extent of her ethical commitment.

By the time I interviewed her, Ruby's relationship with Mary had come to an end. Mary had fallen again while Ruby was away on vacation and her children decided that it would be better for Mary to be placed in an assisted living facility in Virginia rather than continuing to care for her at home. Ruby seemed saddened by the end of the relationship but remarked that she could see that it was in Mary's best interest and that the facility they had moved her into in Virginia was very good. When I asked her if she would like this type of work again she said

¹⁰³ Of course, not every PCA employed as a temporary wage worker would treat demented patients in this way. On the other hand, isolation and sedation *are* typical ways of dealing with elders who suffer under from these conditions. My argument here is that if a PCA is laboring for poverty wages they have very little incentive to choose Ruby's approach to caregiving.

she would and that she was especially interested in jobs where she could travel with the person in her charge explaining that she was free to do so since she had no children of her own.

Independent Conclusions, Ethics in the Context of Exchange

Irma, Kerry and Ruby's alternative/independent health care practices share both a common set of challenges and, potentially, provide us with a key insight into how we might reconceptualize the process of health care reform. Each of these women spent a considerable amount of time talking about the value of the work that they do. While Irma and Kerry spoke of this difficulty in relation to the commercial success of their independent businesses this theme emerged in a different way in my conversation with Ruby—she had a standard of care that exceeded those of her coworkers and the “PCA industry” as a whole.

Each of these women talked about the way that they were transformed by their vocational commitment to caregiving. The process of becoming an ethically committed and professional provider was enabled by their involvement in an independent class process. For Irma this struggle revolved around accepting her place in the market sphere, balancing her desires for her practice to be accessible with the need for it to be successful. Irma's non-market barter exchange reflected her commitment to making her service accessible to everyone while at the same time she tried to make a living. She was in a position to engage in this complex set of exchange relationships because she was self-employed.

In a similar way Kerry wrestled with the idea of how to run a successful practice as an alternative provider. This revolved first around coming to value her own work as an acupressurist, to refuse her position as an exploited wage worker, and second in devising strategies to convince patients and clients to value their

own vital health enough to consider paying for Kerry's services as "money well spent." This process actually involves rigorously inhabiting a position of self-care, insisting that human vitality ought to be more than simply the absence of disease. Kerry was very articulate about how the journey she was asking her clients to undertake—in terms of revaluing themselves and their health—was the same one that she had made in becoming committed to her independent health care practice.

Finally, Ruby clearly held herself to a higher professional standard, one that compelled her to truly identify with and engage her elderly patients. Clearly her status as self-employed allowed her to balance what she needed for a livelihood with a sense of concern for her patient's personal well-being.

It might, at this point, be reasonable for some to object that there is no broader lesson to be learned from these independent practitioners, no new politics of health care reform, since each of these women (with the possible exception of Ruby) markets her services to people who can afford it. If this is the kind of "reform" I am proposing, then would this not lead to a further segmentation of the health care market? Would such a reform create a world where the affluent have the privilege of caring affective labor and careful attention in recreating their bodily well-being while others remain excluded? It might be argued that these women's market-based health care practices reproduce and re-engage disparities in health and well-being along the lines of race, social class, etc. My response would be to argue, first, that the ethical nature of these women's commitments as caregivers is not negated by larger social circumstances. Rather I see in Kerry's call for people to take their own well-being more seriously, and Ruby's commitment to compassionate care, a new standard that should be extended to all of those in

need of care because it can be. It is not their involvement in the independent class process as alternative care providers that is the basis for a new approach to reform but their principled commitment to raising the standard of what counts as quality health care that should be emphasized.

Just like Anasuya and Ashley, each of these women identifies elements within the social context of their work that enliven and enable their capacity to give care and other forces that dampen or diminish it. While their involvement in an independent class process, their engagement in alternative forms of exchange, and their flexibility seem to enable their capacity for ethically engaged caregiving, other forces undermine it. Included within these undermining forces would be the low social valuations of care (especially its alternative and affective dimensions). This social devaluation of care is something that each of these women struggles against internalizing. At the same time Irma, Kerry and Ruby see the possibility of an approach to health care that focuses on much more than the treatment of disease, disability and infirmity. Their efforts seem to revolve around engendering vital relationships (even in the context of exchange), healthy and supple bodies and the preservation of mental facility. It is this focus that really forces us to consider the need for a process of health care reform that revolves around raising our expectations about care and well-being.

CHAPTER VI

ANTAGONISM IN THE “CAPITALIST SECTOR”, HEALTH CARE REFORM IN THE COMMUNITY ECONOMY

Introduction

I began chapter IV by arguing that while health care frequently involves providing emotional services for the patient, the process of doing this work always has affective consequences for caregivers as well. My own interviewees conformed to the expectations generated by other studies and reflections on the caregiving process—namely that it can be at times a deeply moving and rewarding process, a dangerously draining experience or something that is performed as a felt obligation. The split nature of caring labor confirms contemporary theorizations of the autonomy of affect—the split between the “intensity” of care and its emotional (and physical) consequences or meaning. The ethical practice of the caregiver, their self-becoming in relation to care, is located within this split.

In the previous two chapters I argued that both informal caregivers and professional independent (self-employed) caregivers need support in order to remain ethically committed to (and transformed by) the process of caregiving. The diverse/community economy concept allowed us to understand the class and non-class social conditions that enabled this ethical fidelity. For Ashley and Anasuya support from family and community made the difference between seeing their caregiving as a burden imposed upon them—as obligate relation—or a gift that they were giving to the person in their care. Likewise, in a number of ways Irma’s, Kerry’s and Ruby’s involvement in a market-oriented independent class process enabled them to do this work physically and emotionally and it was also what allowed them to engage in practices of exchange (gifting, barter, forms of

intense engagement) that sustained them as ethical subjects, serving as a counter balance against the need to sustain themselves financially. It also was part of what allowed them to be attentive both to their patients and to their own physical and mental needs. In short, the independent class process is what enabled them to be(come) ethical—they were in control of making these decisions. It is precisely the substantive freedoms engendered by non-exploitation that allows us to regard Irma, Kerry and Ruby as ethical subjects.

This connection between affect, ethics, and caregiving allows us to pose the question of how to reform health care in a new way. How can we reform health care so that the caregiver is not simply enabled to care or compensated for their efforts but is in a position to experience their duty ethically, to be transformed by it? I begin chapter VI by describing my interviews with Stan, Cindy, and Sandy. Each of these people is involved—or at least come in regular contact with—what might be called the “capitalist health care sector.”¹⁰⁴

¹⁰⁴ The definition of health care’s capitalist sector is a tricky affair from a class analytic perspective. A pharmaceutical manufacturer like Merck employs thousands of productive and unproductive laborers in order to produce drugs for exchange on the market. The productive laborers doing research, development and manufacturing of a drug like Vioxx must be seen as exploited workers because they are not the first appropriators of the wealth that they produce. The distinction between necessary and surplus labor and the distribution of surplus wealth actualized through the sale of drugs are decisions made by Merck’s board of directors (on behalf of the shareholders). The doctor who prescribed this drug to arthritic patients may be self-employed, part of a worker collective, or (effectively) a wage employee working at a community health center or the branch of an HMO like Kaiser. The hospitals where specialists do their rounds may be a not-for profit or a for-profit corporation. While the physician might staff their ER or cath lab this is essentially a rent or reciprocal exchange relationship—the doctor needs space while the hospital needs the physicians in order to fulfill its social role. Physicians depend upon how hospitals are staffed and administered. Hospitals may provide surgery ward nurses, health aides, lab techs, dispensary workers all of whom are paid an hourly wage—making them productive/exploited laborers in a capitalist class process. From this perspective it doesn’t matter if the hospital is Brigham and Women’s or a branch plant of Columbia HCA—these hospitals are both sites of a capitalist class process.

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
❖ <u>MARKET</u>	❖ <u>WAGE</u>	❖ <u>CAPITALIST</u>
ALTERNATIVE MARKET Local trading systems Underground Barter Co-op exchange Alternative credit	ALTERNATIVE PAID ❖ <u>Cooperative</u> Self-employed Indentured In kind	ALTERNATIVE CAPITALIST ❖ <u>Environmental ethic</u> ❖ <u>Social ethic</u> ❖ <u>State capitalist</u> ❖ <u>Non-profit</u>
NON-MARKET Household flows Gifts Gleaning Indigenous exchange Theft	UNPAID Volunteer Housework Neighborhood Family care	NON-CAPITALIST ❖ <u>Communal</u> Independent Feudal Slave

Figure 6.1: Sandy, Stan and Cindy’s Place in the Diverse Economy

❖=Sandy, Stan and Cindy’s diverse economic activity

They are all clearly committed to as well as inspired and transformed by the process of giving care. While Sandy, Stan and Cindy spent some time talking about being fulfilled by this work, they spent most of the interview talking about feeling undermined by larger social and economic forces. Sandy as a professional nurse and long time union activist described the negative consequences of rationalization in the hospital where he worked. Cindy related her frustrations, both as a professional care coordinator and as the principal care proxy for her mother, with the temp agencies involved in providing home health aide workers. Lastly Stan, a cardiologist, talked about a number of changes in compensation and hospital management that transformed the nature of his work from difficult to impossible.

Each of these people formulated different responses to these forces and circumstances that diminished their capacity to be ethically engaged caregiving subjects. Sandy became actively involved in health care politics at the state, national, and international levels. Cindy and her sister eventually drew on their social networks in the field of nursing in order to find people who could provide the level of care that they felt their mother needed. Stan and his fellow physicians hired a number of people—from consultants to a better secretarial and billing staff—that enabled them to restore the economic viability of their group practice. Each of these interventions was an attempt at retaining/creating the conditions where effective care could be produced in a sustainable manner. Both the ethical and antagonistic dimensions of these interventions can be theorized as a struggle over which class process will predominate in the field of health care.

All of these interviewees were convinced that fundamental changes need to be made in the way that health care is produced and allocated in the United States. While each of them remained committed to the various political struggles they were engaged in, they were also cynical—to differing degrees—about the prospects for change. On a more personal level they felt that the forces of rationalization, bureaucracy and low standards of care were challenges they continued to face in spite of their efforts to address them. These challenges are, I believe, something that can be properly addressed in the context of the diverse/community economy concept.

Challenges to the Fidelity of the Caring Subject

Sandy

Sandy is a sixty-year-old man who has been involved in both critical care nursing and the politics of the Mass Nursing Association for nearly forty years. I

met with Sandy in the fall of 2004 in my office on campus. I was initially expecting a woman to show up as I had only corresponded with him on the Internet in order to arrange this interview. Sandy spoke so readily about his experiences as a nurse and the various political struggles he was engaged in as a union officer of the Mass Nursing Association (MNA) that I had to do little if any prompting.

Hospital Care and Rationalization

Sandy's interview began with a long story about changes in the field of nursing over the past fifteen years. According to Sandy, these changes have made it increasingly difficult to provide the standard of care that registered nurses historically provided. In the area of critical care the fundamental expression of this growing difficulty is a set of changes in what is considered the normal charge of an on-duty registered nurse. The result of these changes is, according to Sandy, an increasingly demoralized profession in which burn-out is so common that it is essentially expected. Sandy's perspective is that the "affordability" of care is much more a matter of how much care (for all) is valued rather than being a strict artifact of the social capacity to produce it.

Sandy began his story, ironically, with a short-lived victory on the part of his union. In the mid-1980s there was a nursing shortage in Massachusetts. Sandy's wife, also a registered nurse, played a pivotal role in filing a labor grievance in an attempt to deal with the staffing shortage. As a result of this grievance, the state passed legislation that allowed hospitals to charge insurance companies more for their services but only if the revenues from these additional charges were used to alleviate staffing shortages. Sandy explained that there was a hiring frenzy, nursing

wages went up 30 percent in a short period of time and things seemed to be going very well for him and his wife at Quincy hospital. However,

Right after that, the Boston University Medical Center/BMC started (along with Quincy Hospital) to consult with job reengineering consultant. They came in and tried to redefine, and they did, nursing as a laundry list of tasks to be performed rather than a relationship with the patient. Then most of those tasks could be farmed out to a lot of unlicensed people for whom they would pay a lot less. And we're still reeling from getting a 30 percent raise. This is even before hospital deregulation and before the managed care revolution and merger mania and all that. This was the late eighties before all of that which is why some of the changes go back fifteen years rather than twelve or thirteen. In October 1989 they built a massive new hospital in Quincy and it coincided with a layoff and, when the dust settled, the new hospital was designed in these little eight bed pods and their plan was to have one RN and one nursing technician for each pod. So then a nurse would now be liable on the nurse/surge floors for eight at a time. Of course at night that could be 10 or 12 or whatever. (Sandy 2004)

Thus not only was the task of nursing redefined but the physical space of the hospital was restructured to normalize the new expectations regarding the productivity of nurses once they had been “freed” from tasks outside of their “core competence.” Sandy went on to explain that as non-profit public sector hospitals continued to merge following the deregulation of the insurance industry in the 1990s, these sorts of work re-engineering processes became more widespread. Hospitals began to merge and to form partnerships and alliances in order to bolster their bargaining power with respect to insurers.

Sandy identified a perverse consequence of mega-mergers as new performance and “profitability” standards took hold amongst for-profit, public sector and other non-profit partnered hospitals.¹⁰⁵ He explained this in relation to

¹⁰⁵ From a Marxian perspective, hospitals run as non-profits are capitalist enterprises by definition if they meet three conditions. (A) They employ wage labor in the production of goods and services. (B) The surplus “wealth” generated from this activity is appropriated by a group of non-producers

the history of his own institution. Boston Public Hospital was taken over by John Silber's Boston University Hospital, which in turn took over Quincy City hospital—privatizing it in effect even though Quincy maintained its mandate as a public hospital.

We are a colony of Boston Medical Center. All of the profitable patients get shipped to the ER or the cath lab there. Umm and we're always considered the poor step child because we have empty beds or we're not making as much money as were expected to. But they are always full and they are always showing a profit whenever there is the annual review of books and so forth (Sandy 2004).

One consequence of this distortion in how hospital performance is recorded is that it leaves the “junior” partners in affiliated hospitals open to another “justifiable” round of re-engineering and rationalization, making the work of nursing even more difficult. According to Sandy, the end result of this process is an intensification of geographic disparities in the levels of care along the lines of the relative incomes of the communities that surround the hospital.¹⁰⁶

(a board of directors). (C) These appropriators are then in a position to distribute this surplus wealth in order to secure the conditions of existence for the hospital. A non-profit hospital is simply a hospital that does not have to allocate some portion of this surplus to local, state and federal government in the form of taxes. However, to be clear, the non-profit status of a hospital comes with a long standing social obligation to serve the community in which the hospital is located. In this regard it is reasonable to imagine that the hospital board is acting as the proxy for the community and that their appropriative and distributive decisions are to reflect the interest of the community. Thus, non-profit hospitals could be thought of as a type of communal enterprise if the hospital workers themselves are considered part of the community of interest being represented by the board of directors and the set of decisions made by the non-profit hospital actually reflect the interests of the community.

¹⁰⁶ Sandy was particularly cogent in explaining why regional variations in care should be of concern to everyone.

You're not going to flip through the Yellow Pages when you are having a heart attack. There is no free market in health care; you are going to the nearest hospital unless the EMTs are on diversion... because we have also downsized a quarter of the hospitals in the last fifteen years. A quarter of hospital beds and they have also slashed the number of patients to nurses. Just starting out in the early 80s three to one was the normal ratio. And I also had support... now I've got to start all my IVs, draw all of my own blood.

Sandy pointed out that the historical attempts at safeguarding uniformity of care access—in the form of a state regulatory board—was a bad system but it was better than the era of hospital deregulation that followed. The chief advocate of hospital deregulation and the introduction of

Fighting the Consequences of Rationalization

The response of Sandy's union to rationalization and workplace re-engineering over the past ten years has been to argue that these efficiency "gains" compromise care quality as well as patient and provider safety. According to Sandy, adequate hospital Staffing levels, RN-to-patient ratios in particular, are the key to ensuring quality. The first argument that Sandy (and his union) makes in relation to this is that nurses, unlike any other health care professionals, are trained to think holistically about the patient. Even if the tasks of checking blood levels, helping the patient relieve themselves, etc., are farmed out to other personnel, it is still the duty of the nurse to determine the patient's overall condition. According to Sandy, unless the nurse is in a position to make an integrative assessment they are not truly engaged in the practice of nursing. It is

private for profit-health care concerns was a Democratic Senator Ed Burke who also had financial ties to Hospital Corporation of America (HCA), the for-profit medical outfit that first made its way into the state.

Sandy argued that there is another completely predictable outcome of this sort of occupational re-engineering/rationalization. When shortcomings in care delivery make themselves known after rationalization, of course hospitals began hiring nurses outside of Massachusetts to fill in the gaps. During a strike in Brockton many "agency nurses" were hired.

Traveling nurses a lot of them come up from the South and they have Southern accents. From the rural south, get big bucks up here. Some of them came during the 100 day Brockton strike during the summer of 2001 to scab and they are still here. So that creates a lot of tension with the unionized nurses. The hospital, and some of them, I was sitting next to her and looking at her schedule and she was working out her time schedule and she was going to work four or five twelve hour shifts in a row. And I said to myself "That's not safe, how can you work like that?"

These nurses have an incentive to work as many hours as they can because of their contractual relations. Shortages in care created by rationalization express themselves internationally as well according to Sandy.

Nurses from South Africa and Botswana are going to UK. Nurses from Ireland are going to BC and people from here have gone up to Canada and Canadians are being recruited to come to the U.S.. The Philippines is a major exporter of health care. Not only this country but in much of the world, so there is a real globalization of labor going on in health care. (Sandy 2004)

For Sandy, the real purpose behind rationalization/job re-engineering is the all-too-familiar belief that its aim is to depress wages and to weaken the power of unions by enlarging the effective labor market.

the affective intensity and intellectual demands associated with this fundamental element of nursing that makes nurse-to-patient ratios a critical issue for Sandy and the MNA.

Sandy explained that his union made use of previous efforts in California when they began to pursue legislative redress. Staffing level legislation had been passed in California by the mid-1990s but really failed to change the situation there because they didn't specifically say what an effective nurse-to-patient ratio was and, secondly, they failed to adequately define nursing. His union—along with other concerned parties such as Mass Senior Action—have over the past several years introduced legislation to guarantee a safe staffing ratio of one nurse for every four patients on ICU and med/surge wards.

In the past year, the MNA marshaled two major pieces of evidence in support of their claims for safe staffing levels and have deployed them in such a way that they hope to avoid the mistakes made by the nurses' union in California. The first piece of evidence came from a study done by researchers at the University of Pennsylvania.¹⁰⁷ Sandy explained that researchers there found that for every patient over four that a nurse is responsible for in a post-surgical ward, there is a 7 percent increase in the risk of mortality. This study clearly points to the need to take nurse-to-patient ratios seriously. The second piece of evidence emerged in relation to the current nursing shortage in Massachusetts and the conflicting proposals for dealing with it. The Mass Hospital Association (MHA) unsurprisingly took the position that more support needs to be given to the nursing programs

¹⁰⁷ See Pennsylvania Health Care Cost Containment Council 2004 for a findings summary.

and that the way to address the problem was to increase the supply of nurses.¹⁰⁸ To counter this claim, the MNA conducted a major survey of nurses working part-time and those who had left the field, union and non-unionized alike. It was found that most of them would be willing to return to full-time work if they could be guaranteed reasonable working conditions including a safe nurse-to-patient ratio.¹⁰⁹ Many respondents indicated that under-staffing is what had led them to abandon nursing or reduce their involvement in it. While the self-employed care providers discussed in chapter V had to make certain that they took care of themselves in order to continue their work—obtaining adequate rest and remuneration for their efforts—Sandy and the MNA have had to consistently argue against standards of care that were, in their view, not only unjust but dangerous.¹¹⁰

¹⁰⁸ There are a few reasons why the MHA would prefer this approach. New nurses are not as well compensated as their senior counterparts. In addition the 'educational solution' increases the number of people in the field of nursing.

¹⁰⁹ Sandy himself is working part-time as a nurse after having cashed out his pension plan when Quincy was privatized. One of his reasons for wishing to go full-time is that he is still trying to accrue quarters to be eligible for Social Security. There are other reasons as well.

I cut back and I am working two twelve-hour shifts a week. . . . Physically and emotionally I can't deal with more than that. I turned sixty a few months ago. I have been taking care of patients for forty years. My free time is mostly taken up with the political fight to try and straighten out this rotten system. I don't have enough energy. (Sandy 2004)

¹¹⁰ I asked Sandy about needle sticks on the job as an issue of work safety. Sandy pointed out that needle sticks are only one of about a dozen factors that affect the health and safety of the nursing staff. Sandy himself had a needle stick incident (his first) six months prior. While Sandy was disturbed by this incident, he was much more concerned with drawing out its political implications. Sandy initially felt that Massachusetts had done the best it could in getting a tough safety standards law passed—which called for only disposable retractable needles to be used—only to find later research that needle stick incidence is much more closely related to issues of staffing.

Needle sticks are probably a hundred times more impacted by the staffing levels and by the amount of control over the working environment rather than having retractable needles or retrofitted needles and the other technical aspects of the law. Now were through and we've won in Massachusetts a very strong needle stick law in terms of the need to be safe. And we've been a model for the rest of the country, but then that research came out about a year ago and sort of blew me away. All that work! I mean it started for me last January when I stuck myself with a needle. I had too many patients than I knew what to do with. . . . And it happened that I stuck myself with a needle right after that giving an insulin

He mentioned his own exhaustion several times during the interview and, like many other caregivers, was concerned about the ability of people to provide quality care under conditions that were physically and emotionally draining.¹¹¹

Commitment to Universal Care

Sandy spent some time with me talking about the efforts of his union to pass legislation to ensure that health care is universally available to all the citizens of Massachusetts. Sandy, despite his exhaustion, seemed tireless in his commitment to this related cause as well. However, he also acknowledged that passing legislation that guaranteed access to care was only a turning point in the nature of the struggle. Here his long-term association with nursing unions in Canada convinced him of this.

Down here we hear everything bad that happens as proof that such a system can't work. . . . But like everything else it involves people, and it involves struggle. Let's take Alberta, probably one of the richest provinces, lot of oil up there. And the Tory Prime Minister Ralph Klein has been particularly interested in undermining the public sector, social insurance. He actually, by under-funding—and part of the under-funding did come from the federal government—

injection to a patient, an hour later than I should have because I just never got to it. And the occupational health nurse writes you up, basically for not using the system the way that it is supposed to be used and I said, well let me do a little research on this. And I brought it back and said "here read this!" You know there is evidence out there that staffing levels and the nature of the work environment have a lot more to do with needle sticks than whatever kind of needle you happen to buy.(Sandy 2004)

¹¹¹ Sandy was more reluctant than my other interviewees to diverge from the politics of health care reform and to explicitly talk about his affective and ethical investment in care providing. Based on everything that he said in the course of the interview I believe that his political convictions to fight for the quality, accessibility and availability of health care for all comes from a belief that anything less than that is bad for care providers. One explanation for his reluctance to talk about the “emotional” aspects of providing caring labor is that he either regards them as a political liability (a sort of giving into the feminized representation of his profession). Another is that this reluctance could be a product of his training as a nurse. Cindy, who was completing nursing school during the time that I interviewed her, said that nurses are trained to be attentive of the needs of others without betraying their own emotional investment. This does not mean that nursing is without affective/emotional consequences for care providers but rather that the space of care requires this asymmetry of emotion in order to function. This parallels the dynamics of analysis; the analysand is encouraged to divulge their feelings by the “enigmatic” posture of the analyst.

like anything else if you've got a budget you will cost shift. And so there were long waiting lists for surgery (Sandy 2004).

Shortfalls in funding are the product of deliberate policies on the part of the provincial and federal governments in Canada. They create the same sort of budgetary strain and political pressure that are exhibited in relation to Medicaid in the United States. According to Sandy, conservatives use the “scarcity” created by budgetary shortfalls to create a political climate more amenable to privatization. It is also true, however, that Canadian nursing unions are in a position to resist some of these political maneuvers.

I mentioned Manitoba, now I am talking about Alberta. And he [the Premier Robert Klein] said, oh we've got a solution, let's bring in this American company and open up some for-profit surgery centers, which is a direct violation of the Canada Health Act and created a political turmoil and I am proud to say that the organized nurses are amongst the most powerful opponents against bringing neoliberalism to health care up there. (Sandy 2004)

Sandy seemed to feel that documenting the ongoing struggles of nurses' unions in the United States and around the world in his online journal *Seachange* was of paramount importance in continuing to assure access to affordable quality health care. Sandy was very clear that the growth of partnerships among hospitals, the emergence of private for-profit health care, and prevalence of job re-engineering all constituted significant threats to quality care. His involvement in the politics of the Mass Nursing Association is his way of expressing ethical fidelity to an underlying belief that health care was a fundamental right that would only be guaranteed by collective vigilance on the part of health care professionals.

Community Involvement in Care?

Towards the end of the interview I asked Sandy what role families and community members might play in the process of providing care as well as the

politics of health care reform. He saw the general public as potential ally that was in need of political education. He told me, for instance, about an ad campaign his union launched that explained to people that when a nurse has a relative in a hospital they generally stay at that person's bedside in order to make sure that their relative does not become a medical error statistic. This campaign was successful and while some nurses complain about the intrusive presence of families trying to ensure their family member's safety, Sandy feels that this is ultimately a positive development because it might lead them to question why it is that hospitals are so hard-pressed to deliver safe quality care.

At the end of the interview, after I had shut off the recorder, Sandy voiced some misgivings about including "stakeholders" in making decisions about hospital governance. In his view, it was easy for hospital management to persuade citizen stakeholders operating in an oversight capacity that they were the voice of reason because, in part, adherence to the "bottom line" is a common sense. According to Sandy, nurses and other professionals, with their demands for more staffing or a safer working environment, are almost inevitably regarded from this bottom line perspective as unreasonable, biased, or self-interested.

I was taken aback by this reaction since I imagined that Sandy would readily warm to the idea of building alliances between his union and the public they are trying to serve.¹¹² Sandy seems to insist that it is the nursing staff that

¹¹² I thought about bringing up the work of Savage (2004) who documents the efforts of a group of unions, spearheaded by SEIU local 285, to control the effects of a merger between a public and a private hospital in Boston. Their aim was not to prevent the merger but to insist that the new entity retain its commitment to provide care for all. The unions targeted the city council—overseeing the merger—for their political action because

Ironically, the city council had passed a residency requirement for city workers based on the assumption that city payroll dollars would stay in the city—however, so did the votes. One city councilor estimated that there were 20,000 city

possesses the expertise on how hospitals should be governed and that a properly enlightened public should simply endorse whatever they deem appropriate. On the other hand, there were other moments when Sandy lamented the demise of the parts of his nursing job that brought him into a working relationship with the same public as patients and their family members. Sandy describes how an institutionally supported practice of paying nurses to do cardiac education was abandoned.

When we had a cardiac education program one of us would come off the floor three weeks at time doing nothing but teaching patients and their families about risk factors and life style change. Now the theme was “Well everyone should be doing the cardiac education!” But now no one was doing the cardiac education that was needed because it was through put... push them through the system as quickly as we can. (Sandy 2004)

For Sandy this was an example of a working relationship between nurses and patient’s families that was terminated by the process of hospital rationalization. While Sandy has expressed some reservations about an abstract public being included in the governance of hospitals as “stakeholders,” he appears far more receptive to the idea of the families of patients being actively involved in the care of patients. How might the diverse/community economy concept help replace the notion of an abstract citizen “stakeholder” with a community economic subject whose caregiving work readily allies them with the concerns of the MNA?

employees, and only 40,000 people had voted in the previous city election. He calculated that, even if a small percentage of city workers voted, they would be the largest constituency (Savage 2004, 559).

Savage goes on to describe how the unions of this local hospital were able to retain unionized employment and preserve the mandate of the hospital to serve the needs of the entire community. The reason why I couldn’t bring this up with Sandy was that the hospital Savage was writing about was Boston Medical Center. The reasoning behind Savage’s argument is sound. The unions were using the “stickiness” of their industry in order to mobilize across organizations and in the community in order to achieve certain outcomes. From this perspective the negative outcomes of

Do we not have here once, again, an instance where Nancy's distinction between "common-being" and "being-in-common" becomes relevant (1991, 1992a)? Recall that common-being refers to a politics of inclusion that imagines "community" in relation to a common essence. Nancy points out that "common-being" inherently tends toward the totalitarian since it defines the community through exclusion. In contrast to this exclusionary definition of community Nancy poses its opposite—"being-in-common." Here, what is recognized as common to all is simply an existence without essence. Community, rather than being a definite thing, is a process of interaction, of "comparing," in a way that underscores our "being-in-common."

Is it possible that Sandy's reluctance to embrace the "community friendly" notion of a stakeholder is a resistance to the formulation of a common-being? With this possibility the interests of stakeholders would be fused to the economic viability of the hospital—as defined by management. Those who are excluded from the common-being are regrettable casualties whose need for care must be "balanced" against the survival of the hospital. Against this we would pose Sandy's nascent recognition of a being-in-common. It is possible for politicized nurses, patients and their family members alike to recognize the difference between a safe work place where quality care is possible and one that is dangerous, understaffed and devitalizing.

Sandy clearly has an ethical commitment to the accessibility and quality of health care provided by registered nurses in the hospital setting. While he is committed to a politics of antagonism within the hospital setting, he seems

the partnerships that Sandy describes/decies can either be seen as an inevitable contradiction or,

ambivalent about connecting with potential allies in the broader community. Whether “the public” is composed of family members of patients, and fellow caregivers or a mass easily manipulated by hospital administrators depends upon the connection we might make between formal and informal care providers, hospital and home based care. The diverse and community economy concept gives us a way of theorizing that connection in a way that recasts what it means to be a stakeholder.

Cindy

I interviewed Cindy at Smith College in April 2005. Cindy is a fifty-one year old resident of western Massachusetts. She talked to me about her extensive involvement in the health care field—as a care assessment and coordinator and as the owner of an Limited Liability Corporation in the same field, as an informal care provider for both her father and mother as they transitioned into death and, finally, as a soon-to-graduate nursing student in the process of assuming a post in the neurology ward of a local hospital. Like Sandy, Cindy was very articulate and needed little if any encouragement to speak about her experiences as a care provider.

Cindy and I spent most of our time discussing how she and her family provided palliative care for both her mother and father, though this ended up relating to her professional experiences as a care provider in a number of ways. Cindy had experiences as both an employee in the care coordination field and later as the owner of a small business that provided assessment, coordination of services and, if necessary, placement in a nursing home. She felt these experiences

perhaps, as a missed opportunity to link with other community-unions and stakeholders.

prepared her for the frustrating experience of taking care of her own mother. In the course of relating this story, Cindy commented on the many shortcomings of the present system, from inferior home care to inadequate hospital care.

She began her story by relating the tragic consequences of her father's stubborn attempt to care for his wife without burdening anyone else in the family. From Cindy's perspective the exhaustion and strain of taking care of her mom, who was suffering from a neurodegenerative disease, was the cause of his fatal heart attack. If Ashley and Anasuya's stories represent a successful instance of informal caregiving labor, Cindy's father's experience bears witness to the tragic consequences of an older person's attempts to be a primary informal caregiver in the absence of any social support.

It was at this point Cindy and her siblings became increasingly involved in caring for their mother. Eventually Cindy's mother was confined to her bed not from the progression of her illness but from a fall that broke her hip. After being hospitalized for this, she had developed contact sores, due in large part to the negligence of hospital staff. Her mother faced months of rehabilitation to recover from her break and these lesions on the backs of her feet and elsewhere made her recuperation even more laborious.¹¹³ Cindy's mom was eligible, through Medicare, for rehabilitative care from a visiting nurse. This led Cindy to make another ironic observation about the state of geriatric and palliative care. In order for her mother

¹¹³ As Cindy knows from her professional training the only way to avoid contact sores in elderly patients is to move (or have them move themselves) every two hours. This is one of the more labor intensive aspects of the care delivery process and a practice that might difficult to comply with under the working conditions described by Sandy. I asked Cindy what she would think about a machine that could do this automatically. Her immediate and emphatic response, "I certainly hope not!" was, I believe, animated by the recognition that such a development—and the loss of patient-nurse contact—is *not* outside of the realm of possibility.

to remain eligible for care from the visiting nurse, her condition had to show signs of measurable improvement. Because her mother was suffering from a neurodegenerative disease there was only so much improvement possible. At that point the relationship with the visiting nurse was terminated, and the burden of care fell back upon Cindy's family within a short period of time.¹¹⁴

Family Care and the Difficulty with Home Health Aides

For Cindy a critical issue was making sure that her mother was not only cared for but safe from any improper behavior on the part of care providers outside of the family. She first exhausted the option of having live-in care. She said that given her mother's need for continuous care it was impossible for any one individual to do it all. In consultation with her siblings it was decided that they would each take turns caring for their mother and that they would hire home health aides in order to augment their capacities to care for their mother in a home setting. Cindy said repeatedly that she was greatly concerned about the quality of home health aide workers that might be made available to her through businesses, such as specialty temp agencies.

I had had a lot of experience working with these home health agencies and I knew from experience that there was a huge range in quality in terms of these agencies.¹¹⁵ You were going to get the

¹¹⁴ My father's experience was very similar. Because of the progressive nature of his lung disease the visiting nurse who administered his respiratory therapy was only able to document improvement in his condition for a very short period of time before she had to leave.

¹¹⁵ Cindy worked for a number of years as an independent care coordinator. Cindy's work involved assessing the care needs of older individuals and referring them to the kind and level of care appropriate for their needs and means. Her experiences in this profession not only enlightened her as to the state of the industry it also added another level of complexity to this story. She said that she dealt with many of these agencies who provided home health aides when she was a care coordinator. What was remarkable was that in addition to paying these workers so little most of these agencies were less vulnerable to any sort of legal liability—if something should happen in a home to a patient or their possessions—then Cindy was as the care coordinator. While she was clearly dedicated to this business when her own parents became ill the stresses that this business placed upon her were too great to deal with when faced with having to care for her own parents.

person who was like my mother's own daughter and then you were going to get the person who might walk off with her jewelry. . . . I spent four years in that field and boy did I learn how they worked, how they ran and what kind of quality you were going to get. So when I started to provide care for my mother and father I already had many years of experience. . . . I knew what the problems were already which is why, from day one, we had cameras in the house. Right from the beginning because I had seen enough to know that you might land that lemon in the group, if you will, amongst a group of great women doing this home care you are going to land that one that's going to ruin it for everyone. So I knew enough when we started to put certain safeguards in place for my parents. (Cindy 2005)

In addition to installing video cameras in the house, her brother eventually chose to move into a house next door to his mother to join her for meals and to supervise the work that was being done.

His moving next store is what really made it work because he kept such a close eye on what was going on. That there was never a chance for the people who were by and large wonderful with a few exceptions, there were a few people who took advantage of the situation. When you have a health situation where the person being taken care of is no longer a reliable reporter they are no longer able to report on what is going on in the house. Once that capacity is gone, then the people that you have there you have to place a great deal of trust in. (Cindy 2005)

The people who were working for Cindy were informed of the cameras. In spite of this, one worker was dismissed when it was discovered that she had left Cindy's mother unattended for several hours. It is perhaps difficult to justify this type of invasive supervision. Cindy insisted that this type of surveillance was necessary given what she knew about home health aide businesses even though she recognizes that her efforts might have appeared peculiar, paranoid, or worse.¹¹⁶

¹¹⁶ Perhaps what seems odd is that it would be necessary to turn one's home into a space of surveillance. These efforts are familiar to us in other workplace settings as a way of discouraging theft and laziness. It was also clear that it was a very uncomfortable thing to have to do, to exhibit that level of mistrust in one's home.

Eventually, when Cindy entered nursing school she and her sister, who was already a nurse, were able to find people in whom they could place a lot of trust to be part-time care takers for their mother. These people also were carefully screened but Cindy and her family grew to trust them much more than the “strangers” they hired through the temp agencies. From a class analytic perspective these individuals would be considered self-appropriating independents, though Cindy insists that these people identified with their charge as if they were family and that they eventually became family. When I asked her to explain what she meant by “family” she explained:

It's about how caring and compassionate they were towards my mother [beyond] the financial portion of the relationship. The financial portion of the relationship kind of recedes into the background and the interpersonal skills that they brought to my mother, their technical skills as RNs and as aides, those skills are so valued by the family. The kind of compassion and care that they showed for my mother, it kind of explodes the boundaries of the box. The boundaries of an economic relationship, those walls get pushed out and suddenly the relationship is no longer in that box anymore. And, you learn about their problem, their families.... There's enough interaction over time that a real personal relationship develops and, if anything, you feel bad that you can't pay them more. Because you have to stretch and stretch whatever resources you have to pay for all of this. This is a very expensive proposition and very few people can afford to do this. (Cindy 2005)

The standard of care quality that Cindy articulates here is interesting—the best care you can buy resembles the care freely given by family members. Certainly, mobilizing a rhetoric of family is commonplace in the health care field. As we learned from the previous chapter, however, from the perspective of class analysis, caregivers who are involved in a non-exploitative class processes (independent or communal) are perhaps more capable of inhabiting their work as ethical subjects. Cindy felt that adequate remuneration was one of the key factors in assuring quality care. Most of the home health aides that she would have hired through

agencies were being paid minimum wage or slightly above it. Cindy and her family were paying individuals above the industry average, an expensive proposition that, Cindy admits, would have been impossible were it not for her mother's financial resources.¹¹⁷

Imagining the Future of Care

I asked Cindy to think about what an ideal elder care system would look like. Cindy began her answer to this question by asserting that the “extended family” constitutes the optimum caregiving environment. She explained that this was a viable solution in the time of when her father was a young man.

My father grew up in a neighborhood where all the extended family lived in walking distance. Even though they were poor by any measure it was the happiest time of his life. He considered himself to be born at the best time in history. Unfortunately he had to go through the war and the Depression but there was such a sense of community and people were physically close to one another [in Lawrence, Mass]. He lived in a neighborhood where everybody he went to school with, everybody in his family lived within walking distance and so there was a network of support there throughout his childhood and he said it didn't matter what they had economically because that sense of community that they had is, doesn't exist any more. (Cindy 2005)

Cindy seems to articulate here a commonplace belief that the sense of community was strongest in the U.S. during the Second World War and post war period. This is a perspective shared in both academic circles and popular culture (e.g., Putnam 1996).¹¹⁸ Cindy pointed out that having your parents live with you when they

¹¹⁷ She estimated she was paying (out of her mother's savings) between two and three hundred dollars a day for home care.

¹¹⁸ I realize that in treating Cindy's remarks uncritically that I am perhaps engaging in the “romance of community” or an exercise in nostalgia. On the other hand class analysis supplies us, potentially, with a way of theorizing the household and extended household to reveal the range of processes that might have shape the capacity for care both then and now. It is possible that one could have an extended family that was ruled by a despotic patriarch who might direct or withhold caring labor from other members of the family as a way of exercising authority. On the other hand,

became elderly was a normal thing only a few decades ago. I asked if she thought personal mobility was to blame for the demise of this practice. Her response began with the observation that

Even if mobility were not a factor, we live in nuclear families now, we don't live in extended families, even if you live in the same town. My parents grew up with the elders living with the families. They died at home and they lived at home throughout their decline and difficult years. There is a lot of people out there involved in informal caregiving, there are a lot of people struggling to do it and making great sacrifices to do it. It is a great sacrifice to take your parents in when you are still raising your children. That's why they are called the sandwich generation. . . I believe with the arrival of antibiotics and advanced medical procedures, people are living so much longer. People didn't live the extra fifteen or twenty years that they do now. So even if mom and dad did live with you they probably didn't live, in the numbers that they now are living to be eighty. So you might have mom living in your home but they didn't live to 102. My husband's mom died at 102. A lot of people now live into their eighties and nineties. But before antibiotics there was pneumonia. My father had four angioplasties to his heart. And he succumbed because he was a caregiver. Ah, but he had four angioplasties and he died at 75 and not that many years ago he would have died at 65. (Cindy 2005)

So not only is the nuclear family left to do an extended family's job, they are apt to do it for a much longer time than the generations of informal care providers before them. The conclusion of Cindy's story seems to leave us a difficult choice. We can see her reflections on care in the context of the extended family purely as a type of nostalgia or we can see the present efforts of Cindy and her siblings as an attempt at creating an extended "family." We might even be inclined to regard the caring labor of Cindy and her siblings as a communal labor augmented by the efforts of independents. The creation and financing of the family-based network was directed by an ethical concern for their mother's well-being, dignity, and

it also becomes possible to see Cindy's father's recollection as reflecting another, perhaps more communal extended family.

freedom from harm. The question becomes how can we reform health care so that it becomes possible for those in similar circumstances to fulfill their duty even if they lack Cindy's social connections and financial means? One answer that is left unexplored in policy circles is the possibility of a home health aide enterprise that is run under a different set of conditions—one where low wages and little loyalty are not the predominating feature of work-life. What if there were home health aide enterprises run on a cooperative basis that performed a similar function to Cindy's network? Alternatively, what if there were more independent care providers like Ruby? As I will discuss in concluding this chapter, this question does not need to be posed in a speculative manner.

Stan

I spoke with "Stan" on two separate occasions. I first interviewed him in 2001 about his western Massachusetts group practice and then in early 2005 when I had learned that he and his practice had gone through a major reorganization and shift in focus. Stan is a member of a four-person cardiology practice. The cardiologists in his practice offer an array of services for patients. Stan had gone through the extra training required to become an interventionist, learning how to place stents in the arteries of the heart. He provided this service to both the patients of his practice and on an emergency basis when he was on call in one of the three different area hospitals.

Communal Practice and Thinking Like a Physician

In class analytic terms Stan's cardiology practice is a cooperative or communal enterprise. Revenues from the members of Stan's practice are pooled and, after expenses are met, are divided evenly amongst the members. Likewise, decisions made by the practice—adding or dropping a particular diagnostic or

interventionist procedure, who to hire as an accountant, etc—were made collectively. These decisions affect the non-productive expenses the cooperative incurs and, in turn, partially determine the boundary between necessary and surplus labor. Stan explained that part of the reason for running their business as a democratic collective is that it engendered a particular spirit of cooperation amongst the members.

Other practices, Stan explained, were essentially run as a collection of independent physicians who happened to be sharing office space. In practices of this sort the compensation of each individual physician was tied to the number of patients they treated. We referred to this organizational form in the interview as Plan B. Plan B, in Stan's view, has inherent flaws.

We thought that even though we might try not to think about money, if all our activities generated dollars that went to us individually, your "Plan B," then we might race to do a consult or trip over each other to do EKGs. We'd just be competing with each other, even though we didn't intend to. There'd be that unconscious motivation there. We just wanted to eliminate any possibility of that sort of corruption within the group. We wanted to not have to think about money. So we just do our job, the money comes in, we divide it and move on. (Stan 2001)

In the Plan B scenario, some physicians might also be inclined to shirk on their responsibilities.¹¹⁹ In contrast, according to Stan, paying everyone the same amount

¹¹⁹ "Stan" was quite convinced that a collectivist orientation in a group practice created a superior work climate by engendering a particular attitude amongst the members of the practice. One can see how specialty practice such as Stan's both requires a high degree of cooperation. Plan B presents physicians with the temptation to maximize their own income. Another physician we interviewed in the course of our research was a general practitioner, "Mike." His office was located in a small rural hill town on the outskirts of Northampton, Massachusetts. He shared a practice with an older doctor. They essentially operated like two independent physicians who split expenses. However, they jointly decided that the person with the lion's share of the office time would also pay a higher proportion of the associated nonproductive costs—office staff, rent, utilities, etc. They also occasionally cooperated with one another by seeing one another's patients when it was necessary. They had a particular rationale for *not* pooling revenue streams and taking an equal share of the income:

creates a sort of enforcement mechanism where everyone has an investment in making sure that everyone else was pulling their weight in terms of the collective practice.

Stan said that this organizational form (and its “coercive” element) also helps them to “think” in a particular way.

We don't like to think of ourselves as business people. I mean, it's nice to make money. Everyone likes to make money. But we like to think and act like physicians, not like business people. So that helps us remove that consciousness. (Stan 2001)

In 2001 to “think and act like physician” meant leaving the process of billing, getting paid, and deciding who to write off as free care (and how much) to the office manager. He admitted that this is a potential source of trouble for physician practices, while also being cognizant of the fact that ignorance allowed him and the members of his collective to act in a certain way.

Practices have trouble when they are losing money practicing medicine, which is happening more and more, fortunately not to us

Part of it (the independent arrangement) is that it basically allowed us the flexibility without anyone having to feel that they were working harder and not getting any benefit from it. And it also was letting the person who was working less not suffer as much as if they had to split the expenses. So it was both to reward the person who worked more as well as to not punish the person who worked less. And that way, yeah I think no matter how altruistic you are some of those things can grate on you. (Mike 2001)

The remarkable thing in Mike's statement is that he sees this way of handling the economics of his two-person general practice as a way of making sure that “money issues” do not unduly interfere with the working relationship between him and his partner in a way that would negatively influence their ability to practice medicine. At another point in the interview he explains that this arrangement allowed them to respond to other contingencies while establishing a sort of minimum amount of work/cost sharing that constituted membership in the practice:

At one point my partner had a health problem. He cut back, it really dropped the amount of time that he was in the office. And his percentage of the receipts dropped to around thirty-eight percent. And we talked about it, you know, at one point there would be a floor. And we decided that it would be somewhere around thirty-five percent. And we also used that as an index, as a time to talk about bringing in another person to do some of the work because you know we are geared up with a support staff for essentially two full-time jobs. So that would mean that he was essentially half-time and we could then think about hiring a person to fill that vacancy. (Mike 2001)

yet. We treat a lot of people for free. If we see someone with heart disease and they don't have any (insurance), we don't know who is insured and who isn't, we don't, that's something the manager deals with. We just treat people. And if they don't have money and they don't have insurance we just treat them. It's not relevant. They're all treated the same. (Stan 2001)

A Precarious Balance

This, of course, does not mean that the way that care is financed, the balance of insured and uninsured patients, is not affecting the viability of his practice. By his estimate, Stan's practice was getting paid for 14 percent of the work that they were actually doing. Much of this had to do with the difficulties associated with billing multiple insurers for procedures—frequently having to submit the same bill a number of times for a specified service before receiving any income. While submitting bills did not always result in payment it did drive up with the cost of non-productive clerical labor. At the same time a number of forces were conspiring to make this precarious balancing act even more difficult:

I am thinking an angioplasty costs about \$5000. That includes hospital expenses, blood work, nursing salary; everything taken into account is about roughly \$5000. And ten years ago I think a doctor got about \$1800 for it. Now it's about \$600. The angioplasty is not just a procedure. I mean it's a procedure, but you also have to determine who should have one and who shouldn't. You see the patient maybe a day in advance but you are looking after them that night, days you might spend hours talking to the family. It's a whole process that takes a lot of timing and training to do. It's not just a procedure that takes an hour. (Stan 2001)

The value of the procedure is effectively determined by the government. In 2001 the reimbursement rate was already falling. Medicare says what they are willing to pay for and after that is established, insurance companies tend to follow suit. The rates of reimbursement, at least as it relates to angioplasty, have steadily been going down while the percentage claimed by the hospital for overhead has steadily risen.

A lot of that goes to the bureaucracies. Administrative costs have increased wildly and that's just a self-perpetuating phenomenon. Administrators breed more administrators like rabbits. So that's a self-perpetuating trend. Unless there's a nuclear explosion or something and we start fresh. (Stan 2001)¹²⁰

Crisis and Reorganization

In 2001 Stan seemed happy with his practice and with being a surgical physician. I spoke with Stan in 2005, after learning that his life and professional practice had undergone a major shift. His practice had restructured in response to several pressures—they had hired another person, expanded their diagnostic facilities and hired additional support staff. Collectively they had also decided to give away their angioplasty practice.

The tensions that he identified years earlier—rising costs (hospitals taking a larger percentage) and declining rates of reimbursement—had taken their toll on his practice. The worsening financial situation prompted Stan's collective to make a number of decisions that changed the organization of their practice. Stan also spoke about shifts in the institutional and workplace culture that factored into

¹²⁰ Stan connected this insight in a sort of anecdotal way to the working conditions of hospital staff and physicians. He explained that at a major Springfield Massachusetts hospital there was one unisex locker room that was typically shared by a staff of forty. People would always be in various stages of undress and it was one of the locations where much of the jocularity that is so important to one's emotional state occurred. He contrasted the poverty of these facilities for staff with the high tech setting of the hospital itself.

A year or so later he came to me with another story. He was getting his security pass reauthorized after spending a night at the hospital sleeping in a "room" that had been set up for physicians who had to do emergency overnights. The room was essentially a janitorial closet with a mattress on the floor with no sheets or bed covering. The security worker, not knowing who Stan was, asked him what level of clearance he needed. He thought about it for a moment and realized this was his opportunity to see how the other half lived.

His new security pass allowed him to get into the administrative portions of the building that had been newly built with gleaming marble floors. The thing that impressed him the most however was the executive washroom which contained generous wash basins, beautiful floors, and plush towels. He told me he would have much rather spent the night in the executive washroom than stay in the "room" that was set aside for overnight physicians. When I asked him about why there might be this disparity in terms of the working conditions of physicians vs. hospital management his answer was that there had been an evolution in hospital culture where it was believed that expert management was what was necessary to run a hospital and, since they were in scarce

these re-organizational decisions along with a personal reevaluation of his priorities. While these shifts were prompted partially by a profitability crisis in the firm, he also saw all of these changes as what would continue to enable him to be a physician.

The interview began almost where we had left off years earlier with Stan commenting on how changes in the rates of Medicare reimbursement began to play an ever more central role in how his practice operated:

There were four of us. And we were working more and more and people (patients) are getting older and older and the workload has just steadily increased. Every year we're working more and more and making less and less... The volume has gone up. The average patient twenty five years ago would have been fifty but now they're seventy. They're seventy and they're sicker. Their cases are more complicated. So that's happening but there are also profit issues that are beyond our control. A lot of it is Medicare related. The reimbursement rates are steadily dropping so we're working more and making less, every year. (Stan 2005)

The crisis that Stan identified in 2001 had grown steadily worse in the intervening years. The solution that Stan and his practice initially tried was to add an additional physician to their collective, an approach which ultimately engendered more difficulties. While their workloads were slightly less the associated support expenses had gone up—so that essentially they were still jogging in place from a financial perspective.

When adding another physician failed to address the crisis of increasing workloads and a falling rate of profit, Stan and his collective members were prompted to completely rethink their entire operation. They hired a consultant

supply, everything should be done to attract and retain them. This is of course a familiar story which justifies high levels of executive compensation in many different fields.

who was instrumental in making many changes—beginning with the way that they were billing.

Stan: She looked at what we were doing and was able to show us that we were just losing hundreds and hundreds of thousand of dollars not from the way that we were working but the way that we were billing....We were undercharging. Which sounds stupid, but Medicare is a really convoluted complex system. There is a Medicare book that is literally like eight inches thick on how to bill. You need a degree in it to understand it but you can hire someone to help you. So we were consistently undercharging.

Stephen: And you had a person in place to do that Medicare billing?

Stan: No, we were guessing.

Stephen: How many of your charges are Medicare patients?

Stan: 60 percent. We were asleep at the wheel with our administration. We were doing okay for a while because we kept our costs so low. But we were fooling ourselves because our overhead was so low that we lost hundreds of thousands of dollars that way because our billing person was overwhelmed and we didn't really understand that. There was just more work than she could do. . . . She didn't say anything. There were countless things that went unbilled. Since I joined the practice a decade ago we figured that probably there was a million dollars worth of work where we didn't just send the bills out. Just didn't send it. (Stan 2005)

The consultant also suggested that they subcontract a billing agency rather than employ someone to do billing in house. Stan explained both the necessity behind this development and its principal advantages:

We contracted to a billing company. It's a whole interesting phenomenon. We interviewed several of them. It's a relatively new business that arose because billing has become so complex. You don't have to deal with all the personalities of hiring someone. (Stan 2005)

The billing firm had the labor power to be able to negotiate the reimbursement procedures associated with Medicare. Stan suggested that this arrangement worked much better because they, unlike an hourly employee, had a financial

incentive to charge as much as they could within the limits of the law since they were compensated for their efforts on a percentage basis.

The consultant also suggested that several changes be made to the practice to enhance its commercial viability. They expanded the range of diagnostic services available, a change that ultimately required them to move to a larger building to accommodate the stress test and other machines. These growing pains were difficult, precipitating a host of other changes. They bought a new building which posed a huge financial challenge to the firm initially but, since 2002, the costs of the new facility have begun to dissipate. Of course they also needed to hire others to support them in their expanded operation:

Stan: We hired clerical and medical. We have a receptionist and an exit person, a scheduler, office manager and we hired this person to go after these old bills. And she's so nice. She was actually able to scrape up a couple of hundred thousand dollars. And she was so effective at what she's done, a shmorgesborg of activities. She was so good that we hired her part-time to scrutinize every bill that gets sent out to make sure that we are not over- billing or under-billing. She looks at everything that goes out to make sure that we stay within legal limits and were not undercharging. (Stan 2005)

Apart from the woman they hired to comb the backlog of unsubmitted bills, most of these hires—receptionists, technicians, etc.—were related to making the new diagnostic equipment generate a profit for the practice. Simply “seeing” patients paid for overhead expenses. Diagnostic services are what generate a profit for the practice.

Ultimately Stan felt that the addition of these new services did not result in an over all increase in the profitability of the firm. While these changes allowed them to stay in business, they also planted a seed in Stan’s mind that the meaning of greater financial stability is that he might be able to work less and actually enjoy himself more without compromising his capacity to save for retirement.

Giving up Angioplasty

For a number of reasons one of the casualties of the reorganization was Stan's practice in interventionist medicine. Stan's thoughts on the loss of this aspect of the practice, the reasons behind it, and its contradictory implications for him were understandably complex.

For years it was fun enough just to sustain itself for me. And also it was profitable so I was encouraged to do it. But then it reached the point where the reimbursement for it dropped, it was a really inefficient process for us because you couldn't schedule an angioplasty really, just a small percentage. The rest would occur emergently. So it may mean that I would have to run off and do an angioplasty and cancel my whole office full of patients. Which, one, was a little unfair. Number two, any profit that I brought through doing an angioplasty was partially negated or even lost through missed patients. But then I could spend hours doing an angioplasty and not get anything for it. So from the perspective of economics, it got to the point where it was neutral at best. It put me in a position where my partners didn't care whether I did it or not. It was completely up to me. And with some mixed feelings for a while, this was extra training, there's a second set of boards, I put a lot into it, I decided to give up. (Stan 2005)

Stan ended up saying that as a physician in his mid-fifties, regularity, not having to work late nights and a scheduled fitness routine were certainly more important to him at this point in his life than any thrill or prestige that he got from being a cardiac surgeon.

While the fact that there was negligible or even negative income coming into the practice through his angioplasties certainly made his decision easier there were other factors at work in his decision as well. One of these factors was a set of institutional changes at Baystate hospital in Springfield which made being an interventionist unbearable for Stan. Baystate management had decided to make the hospital a cardiac care center of excellence.

They wanted to advertise that if you have a heart attack you would be in the operating room within twenty minutes. They started measuring us from the moment that they called to the moment that you are there, to the second. Which was sort of okay but it really diminished your ability to think about it. (Stan 2005)

Stan understood that it is important to measure performance. In his view, this new standard broke the chain of command and made Baystate totally dysfunctional. Stan explained that almost anyone involved in cardiac care, from ER nurses to young interns, could call him and the shot clock would immediately start ticking. Given that everyone at the hospital has multiple responsibilities, and there was little accountability, often the cardiologist would be called as the “first resort” since they were contractually obligated to appear within twenty minutes. Stan speculated that this was the path of least resistance for hospital staff but it was frequently a major waste of his time and income earning potential.

I would be flying down to Baystate knowing that every second was being measured and then I would see someone that doesn't even have heart disease and I would say "you've got to be kidding me..." Then it would be four o'clock in the morning and it would be too late to drive home. And there was no bed there for us so I would just have to pull up a chair or couch. It just got to be really unpleasant. It went on for a while. (Stan 2005)

As these calls became more and more frequent, Stan said that he just could not take it anymore—that this “telephone torture” was sapping his will to live. Stan felt like this idea of a center of excellence could have worked if there had been some way of insulating the surgeons from calls that were ultimately irrelevant to cardiac care.¹²¹ While he says he occasionally misses his practice as a cardiac

¹²¹ One can sort of see why this aspect of design might have been overlooked by the hospital since their bottom line does not suffer when Stan is called in to visit with patients who may or may not have heart disease.

surgeon the benefits to his professional and personal life outweigh this sense of loss.

Stan and the Crisis in Health Care

Overall, it would seem that the crisis produced by organizational change, increasing levels of work, and falling rates of income, prompted Stan and his partners to become far more involved in managing the business side of the practice. They paid the woman who they had hired to do Medicare back billing to tutor them in the process of submitting medical bills so they would have a basic idea of how the “system” works. Stan began to take an interest in the popular literature on innovative approaches to management. From a class perspective, the practice’s response to the profitability crisis that unfolded between 2001 and 2005 was multiple. First, they subcontracted a set of unproductive laborers—the consultancy firm, the billing firm, the Medicare expert—to help them to realize surplus the value that they, the productive workers had generated (in some cases a long time ago). Second, they hired more ancillary staff that could be thought of as productive employees, the techs that help run the equipment that ultimately allowed for the successful diversification of their diagnostic practice. Other staff that they hired would, from a class perspective, be seen as unproductive laborers that enable the productive work to take place (e.g., the receptionist). Both the productive and unproductive staff is not part of the physician’s cooperative but are wage laborers. As a result, from a class perspective, Stan’s cooperative is now engaged in a mixed class process that is at once capitalist and communal, what Levin (2004) refers to as a hybrid enterprise.

Ethics of Care and Universal Access

Stan said that these changes created new expectations in terms of the performance of the members of the practice as well as an increased focus on economic viability. One of the physicians, who was working less than the others, ultimately left the practice because of the changes in workplace culture and what we might think of as a more hands-on approach to managing their enterprise. All of these changes present us with the possibility that Stan is now thinking and acting more like a business man and less like a physician. How did these changes affect his conception of himself as a physician first and foremost? When I put this question to him in 2005, Stan's response re-affirmed the importance of the cooperative approach to business.

Stephen: When I talked to you four years ago, you talked about the work culture created by dividing the revenues after costs evenly. Do you feel that that same workplace culture is helping to renegotiate the work-life balance and other issues within the firm?

Stan: It's helping and really it's the only way that it can be at this point. Because we all work a little bit differently, and some of us, the work that we feed others. It's sort of like a basketball team. You can't just pay the guy that shoots the ball. He wouldn't have the ball if you didn't have the guards, so you have to pay everyone equally. It would just be impossible for us. (Stan 2005)

In 2001 Stan felt that equality of pay was one aspect of the communal enterprise that allowed for a certain type of relationship with work and that having someone else worry about the finances of the enterprise was what allowed them to think and act like physicians. This division of productive and unproductive labor within the cooperative was, for Stan, a condition of existence for his fidelity to the Hippocratic Oath. Stan's second take on the same organizational form

seems to emphasize the interdependence engendered by the cooperative. Now it would appear that the survival of their collective enterprise demands the opposite—they must think and act like businessmen in order to remain physicians. The crucial question from a class perspective is whether their communal arrangement enables them to think about the labor processes and flow of surplus value in a way that allows them to balance the needs of the firm and the demands of the market with their ethical and professional responsibilities. One piece of evidence that suggests an affirmative answer to this question is that Stan's practice continues to provide care for those who cannot afford it. However, this generosity is only possible because they have taken charge of the economic viability of their practice. This suggests to me that actively participating in the management of a communal firm might engender or depend upon an understanding of "business" that is different than what prevails in a conventional capitalist enterprise. In running a communal enterprise one becomes aware of all the non-productive expenses and relationships that enable the communal enterprise to operate productively.

Another piece of evidence that Stan's closer involvement in the management of the firm has renewed his commitment to cooperativism is the shift in his attitude about the Canadian health care system. In 2001, I asked Stan what he thought about the universal government-funded health care system in Canada. His response focused on the way that individual patients in need of cardiac care can end up dying because of the way that hospitals are financed in Canada.

Stephen: What do you think about socialized medicine?

Stan: I think in principle it's OK, but I don't know of anywhere it works well. We look at the Canadian system as something to aspire

to. The Canadian system really is pretty bad. Relative to what the average working American has available to them in this country, the Canadians...uh, it stinks! If you have someone with bad angina, chest pain, in Canada who needs a bypass operation, the average wait is several months. Where in this country, it's days. So not only do you have an attrition rate in Canada that exceeds ours, people die waiting, which is a lot cheaper to die than to get operated on. Saves the system some money. But have someone who is having chest pain every day for months . . . that just would not be accepted here. It wouldn't be tolerated. It's out of the question. It's not a good system.

In 2001 Stan suggested that the ideal health care system would spend just enough money to produce the best medical care available and that some mechanisms should be put in place to assure that there wasn't undue profiting on medical care. Stan was clear in 2001 that hospital administration was a significant cost that, in his view, did not really add anything to the value of care and was, therefore, a form of what he called "exploitative profit."¹²²

Four years later, Stan had revised his estimation of the Canadian health care system. Like Lundberg (2000), Stan came to recognize that Canadians spent far less on cardiac care, tended towards less aggressive and invasive forms of treatments and yet, on aggregate, had the same health care outcomes as their American counterparts. If anything he felt like the wait-times for operating procedures had less to do with the Canadian system as such than with the low expectations on the part of Canadian citizens. He declared that "maybe the problem with Canadians is that they should expect more!"¹²³

¹²² Its important to note that this was his analysis—that supervisory work is ultimately not only "unproductive" but parasitic. Marxian class analysis makes no *a priori* moral judgments about the types of productive or unproductive labor that attends any process of production.

¹²³ This was also a joke, at least partially, since his wife, who was in the other room, has many relations who are Canadians.

This led him to say that while Canadians expected too little, the lesson we might learn from Canada is that we are getting far less than we pay for. He agreed with me that the advantage of the Canadian system is that people can have a public discussion about what to expect and how much to pay. The same conversation cannot be had in the United States because policy is made by administrative experts, while public debate is confined to emotion-laden discussions of the choice between “freedom” and well meaning but misguided “socialist medicine.”

In a sense, Stan’s new-found appreciation of the (proper) politicization of health care parallels his new-found commitment to the management of his practice. Stan and his fellow physicians are more willing to be actively involved in the appropriative and distributive moments of the firm rather than delegating them, or keeping them at a distance. Maybe this led him to generalize this lesson and allowed him to think that if people could become involved, democratically, in making decisions about health care we could have a society that fits his vision for an ideal health care system:

A: I mean, people who make six figure incomes can’t whine too much about their income. We make more money than a lot of people in this country that work very hard. But our income is still steadily dropping year to year, not going up. And the nurses’ salaries may be creeping up, but just creeping. People who actually do the work are not making more money, they’re making less money. I’m not sure where it’s all going. On the other hand, the way I see it, no one should be in a position where they can exploit people for being sick. That’s for sure. But where are we going...I mean, it should be a fair system. Where should money go? I think it is okay to spend money on health care and education and these fundamental things. It’s okay to spend money. I don’t have a problem with that. (Stan 2005)

Ethics and the Capitalist Care Sector

Sandy, Cindy and Stan expressed an ethical commitment to caregiving by struggling against circumstances and processes that undermined their capacities as care-givers. Their collective complaint is that the productive conditions, wage levels or even competitive constraints in health care's "capitalist sector" create conditions that are adverse to effective caregiving. Sandy, for instance, clearly believes that the rationalization that accompanied Quincy Hospital's privatization created a scarcity of nursing care by redefining nursing as a profession. Cindy saw how poverty wages (the extremely low value of necessary labor) in capitalist home health aide enterprises created a toxic work culture while Stan saw how changing levels of reimbursement and the hospital's commitment to "excellence" was gradually sapping his will to be a doctor.

Each of these interviewees responded to the challenges they faced in different ways. Sandy has directed his attention for decades to the political activities of his union. Cindy was unwilling to accept the level of care that would have been provided for her mother by the employees of capitalist home health enterprises and chose instead to rely more on her family and her social network in caring for her mother. Stan and his physician practice responded to the multiple threats to their cooperative practice by completely reorganizing their business.

These interviews suggested a role that the diverse/community economy might play in helping us to theorize the nature of Sandy, Stan and Cindy's efforts to remain ethically engaged caregivers. The diverse economy concept can be used to formally represent how each of these efforts involves a move towards greater communality or what DeMartino (2003) refers to as the pursuit of "class justice". DeMartino points out that it is not necessary to imagine class justice as something

that is only achieved with a thorough going communalization of economic life. Rather it is something that we can pursue in the present conditions. According to DeMartino, this first step in this process is learning to value the absence of exploitation and the presence of communality.

Cultivating a desire for class justice might require arguing persuasively that it is indeed achievable—not just in some deferred future Utopia, but achievable (incrementally) right here, right now. And one vital step in this argument might entail a demonstration that alternative class arrangements, which entail varying degrees of class justice, are already instantiated among us. (DeMartino 2003, 27)

Part of what makes class justice a present day political project for

DeMartino is that he understands how class justice can be pursued in relation to different moments in a class process. DeMartino (2003) points out that just as there are three moments in a given class process there are three types of justice that might be pursued in relation to each moment. Productive justice can have a different meaning and be pursued independently from appropriative justice or distributive justice. While equality of effort might be a prevailing standard in relation to the sphere of production equality may give way to need in relation to the distribution of surplus. Just as there a separate criteria by which we might evaluate what is just in relation to each moment, productive, appropriative or distributive justice might be pursued in relation to any given class process: including capitalism. Justice, for DeMartino, is not an end state but a process of becoming and, in this way, it is similar to the notion of ethics I have been working with here. Sandy was involved in a political process that attempted to redress unjust conditions of production (patient to nurse ratio). Stan and his physicians collective became more intimately involved in managing their firm—pursuing what we might theorize as appropriative and distributive justice. Cindy effectively replaced capitalist home health aide workers with a process of care that combined

paid independents with communal household based caring labor. Here justice had productive, appropriative and distributive dimensions. The language of class analysis gives us a way of describing how Sandy, Stan and Cindy's actions allow them to attend to their psychic and physical capacity for care—though one gets the sense from these interviews that it may be difficult, if not impossible to surmount these obstacles.

While Sandy, Stan and Cindy can be seen to be “anti-capitalist” subjects in this precise sense, how might the challenges they face be addressed in relation to the diverse community economy framework? How might they come to see their political efforts not simply as a struggle against something but as a struggle for a relationship with the community economy? I believe that the answer is that there must be a shift in the way that they conceive of their ethico-political commitments. Ultimately, their efforts must not be one of the conservation of ethical capacity but rather a positive desire for the freedoms and possibilities associated with the community economy. This is something I will pursue in the in chapter VIII.

CHAPTER VII

HEALTH CARE REFORM AND INSTITUTION BUILDING IN THE COMMUNITY ECONOMY

Introduction

Chapter VI concluded with a discussion of the challenges faced by caregivers that attenuate their capacity for ethical engagement. What Sandy, Cindy and Stan have in common is that their caregiving efforts bring them into contact with health care's "capitalist sector": clinics, non-profit hospitals, home health aide agencies, etc. They felt it was difficult to act as an ethically-committed caregiver because of the pace of production, working conditions, and managerial climates in hospitals, or the way that low wages undermine care quality in the home health aide industry.

Sandy, Cindy and Stan responded to these challenges in a variety of ways in an attempt to preserve their capacity to be both affectively present and positively affected by the process of caregiving. Sandy became increasingly involved in political struggles through his union in an effort to reform working conditions in hospitals. Cindy organized a network of skilled independents to care for her mother as an alternative to the low-quality care provided by capitalist home health aide enterprises. Stan and his physician collective completely reorganized their business practice, assuming greater responsibility for appropriating and distributing the surplus wealth in a way that assured the viability of their practice.¹²⁴ Each of these efforts can be understood through the lens of

¹²⁴ Another way of theorizing this from a class perspective is that the physicians in the collective redefined their responsibilities within the enterprise so that unproductive tasks they used to delegate to others now became a central aspect of their productive economic activity.

class analysis as attempts at achieving productive, appropriative and distributive justice.

While none of these efforts produced a caring space—home, clinic, or hospital—free of contradiction or continued difficulties, their narratives, taken together, suggest a new trajectory for health care reform. The more health care can be pushed towards circumstances of collective effort (networks of support, communal enterprises, etc.) and generosity, the greater the viability of the caregiving process.¹²⁵ The more that people are involved in attending to the conditions of their labor (productive justice) and the more that the governance of these spaces are controlled by the community of caregivers and patients (the process of appropriation and distribution), the more these spaces allow for fidelity to an ethics of care.

This chapter will explore a series of interviews I did with progressive administrators of community-based non-profit caregiving institutions. Like the individuals in the previous chapter, these organizations face a number of challenges and constraints that they each have attempted to surmount by soliciting support from the community as well as the local, state and federal governments. While each of these institutions receives (diminishing) support from the state they have also connected with individuals, community groups and other non-profits in their attempts to provide care for the community in their charge. Further, from the institutional representatives I interviewed, I was able to see how the negotiation of these complex relationships with the state and the community is the context of

¹²⁵ One needs to be careful here in distinguishing between the relational networks that typify the community economy (Gibson-Graham 2006) and the rational behind the formation of hospital-networks. Hospital networks are, essentially a type of capital concentration. As Sandy pointed out, this process can actually exacerbate disparities in the level of care.

their ethical deliberation and action. As with my other informants, their approach to care seems to be directed by an underlying drive towards being hospitable to those in need of care and a willingness to be flexible and creative in order to fulfill their perceived duty. What this duty ultimately means for these institutional care providers is both a rejection of a “miserly attitude” and a recognition that choices must be made in order to meet the needs of their communities.

Interviewees

Jay Breines, executive director of Holyoke Health Center (HHC) in Holyoke, Massachusetts, has been involved with community-based health care reform and the administration of community health centers for many years. He described a number of initiatives that involve collaboration with community groups to improve community health in Holyoke; a goal that he feels may be linked with the city’s economic revitalization. Robert Gallant is the executive director of Highland Valley Elder Services (HVES) in Western Massachusetts. HVES is a regional elder care organization that does everything from elder home administration and coordinating meals on wheels delivery to connecting families with home health aides. Frustrated with the financial shortcomings of his organization, Gallant started an alternative currency that he hopes will facilitate mutual aid relationships between differently-abled elders as well as the elderly population and the rest of the community. Lastly, Norman Haug is a “country doctor” in Southeast Colorado who wears many hats, from county coroner to board member on a small HMO. Norman has achieved notoriety by being the first person to obtain a HUD 242 loan in order to build a critical care facility. The new Rio Grande hospital in Del Norte Colorado serves not only the poor residents of the region but also outsiders, from tourists to illegal aliens.

Jay, Robert and Norman all agree that the ability of their organizations to meet local health care needs depends upon their relationship to the greater community—especially the relation to the generosity of the community, volunteer efforts, etc. Their place in the diverse economy diagram is shown in figure 7.1

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
MARKET	WAGE	CAPITALIST
ALTERNATIVE MARKET ♦ <u>Local trading systems</u> Underground Barter Co-op exchange Alternative credit	ALTERNATIVE PAID ♦ <u>Cooperative</u> Self-employed Indentured ♦ <u>In kind</u>	ALTERNATIVE CAPITALIST Environmental ethic Social ethic State capitalist Non-profit
NON-MARKET Household flows ♦ <u>Gifts</u> Gleaning Indigenous exchange Theft Government transfer	UNPAID ♦ <u>Volunteer</u> Housework ♦ <u>Neighborhood</u> Family care	NON-CAPITALIST ♦ <u>Communal</u> Independent Feudal Slave

Figure 7.1: The Place of Alternative Institutions in the Diverse Economy

♦=Holyoke Health Center, Highland Valley Elder Services and the Del Norte Critical Care Facility connect these elements of the diverse economy

The fact that these institutions already exist might lead some to question using them as a model for re-imagining the process of health care reform—they are, after all, part of a system that is currently failing to meet social needs. However, each of the men behind these institutions is attempting to recreate them as something more than merely service agencies for the indigent. Their efforts to gain the support of the community and to meet the needs of the areas they serve insinuate these institutions into a network of relations that compose the

“community economy.” This process involved connecting their institution with other elements recognizable to us as aspects of the diverse economy.¹²⁶

Understanding the efforts taking place in these institutions might also help us respond to the dilemmas and challenges expressed by the interviewees in the previous chapter. Jay Breines offered the tantalizing suggestion that community health centers have the advantages of an HMO but that they are more responsive to the needs of the local community and the physicians who work for them. How might such an organization speak to some of the issues that Stan raised? Robert Gallant spoke of a barter exchange network as a way of extending the caregiving capacity of his institution by linking it with informal caregivers in the community—how might that have made Cindy’s task easier? Finally, Norman Haug suggested that caregiving is simply worth supporting and that all the substantial progress made in rural care delivery has come from a combination of common sense, problem solving, and generosity—how might this insight reframe the sort of struggles Sandy is engaged in? These interviewees have each reoriented the question of how to best reform health care by asking us to imagine the different ways that the spaces and processes of care are sites of antagonism and ethical deliberation. Such an exercise simultaneously involves us in seeing how connections between the various nodes of the diverse economy are, potentially,

¹²⁶ It is, in a sense, no accident that each of these men was interviewed. Two of these interviews grew out of the Rethinking Economy Project’s community conference in May of 2001. From people who attended this community conference we learned about the efforts of Jay Breines and, later Robert Gallant. Both of these men were introduced to us as people who might readily identify themselves and their efforts in relation to the community economy. Norman came to my attention through a relative who, upon hearing about my work, immediately urged me to get in touch with him.

what constitutes the community economy and its ethical subjects. These institutions are sites of community economy that depend upon and enable generosity, cooperation, communality, and a particular disposition towards the care needs of the community. At the same time we must also recognize the provisional and contingent nature of these connections in order to see things as they might be.

Each interviewee expressed the need to think outside of the terms of the dominant discourse that positions health care as a cost to be controlled or minimized. Likewise, each of them wished to struggle against the vision of social-service-providing agencies as “dependents,” as a drag upon the economy at the local, regional, state and national scales. This also is an ethical struggle, an attempt to completely resignify the meaning of caregiving institutions in relation to the economy.

Health Care Institutions in the Context of the Community Economy

Jay Breines

Holyoke Health Center (HHC) is a non-profit organization founded in 1970 to serve the health care needs of Holyoke’s residents, especially its indigent population. Executive director Jay Breines described HHC as a non-profit equivalent of an HMO directed by a board that includes professional staff, patients, and other community members. HHC employs six doctors and a support staff of over one hundred. Doctors accept relatively low salaries when they agree to work for HHC, but they are guaranteed their salaries and are not burdened with the overhead and prohibitive insurance costs associated with private practice (Jay Breines 2002).

Holyoke Health Center: Health Care Reform and Economic Revitalization

HHC is one of sixty community health centers in Massachusetts and one of three thousand nationwide. HHC does between nine and twelve million dollars worth of business each year. The funds that are necessary to pay for the efforts of HHC come from a variety of funding sources and some grants.

In Holyoke we have a very poor population and almost all the people in Holyoke that we take care of are eligible for Medicaid and we get an enhanced Medicaid rate from the government based upon which support services we provide. . . And then we have people that are uninsured that we get paid from a free care pool that the state has, so about two thirds of our revenues come from billing various insurance entities for services provided and about one third of our money comes from state and federal grants. (Jay 2001).

Jay could readily see that this condition of grant/government dependency casts HHC as “just a social service provider.” This suggests to me that he has a vested interest in HHC being seen as something more.¹²⁷ Unlike other businesses, HHC saw downtown Holyoke as an accessible location for their patient base. Jay argues, paradoxically, that precisely because HHC is committed to serving a low-income population, they might be the impetus for a process of economic revitalization/reoccupation of downtown Holyoke. When HHC was awarded a grant in the late 1990s to construct a larger facility, they chose to renovate a building in downtown Holyoke, one block from City Hall.

I think we see ourselves . . . as an economic engine in downtown Holyoke. We are probably involved right now in the single largest development in downtown Holyoke. When the project is finished we'll have probably put together a 12 to 15 million dollar project for downtown Holyoke. To get the banks to fund it is a trick in itself because Holyoke is not seen as a promising economic community and so to put our money into a facility downtown when the bank

¹²⁷ It is worth reflecting on why it is that organizations that serve the needs of the community must prove themselves to be self-sustaining.

has no real expectation as to who would come in and purchase the property for the money that we put into it. Unless you have a reason to be in downtown Holyoke and own a property of that expense, why would you do it? So we are kind of unique, I think the reason we're here is that we're not going to go away soon. The banks have given us some latitude. I'm sure our experience and our longevity is a factor in our potential to repay. (Jay 2002)

This new health care center—La Plaza de Salud—was nearing completion at the time of this interview and has since been finished. In explaining the advantages of the new set of buildings in downtown Holyoke, Jay emphasized that it will enable them to consolidate all of the services offered by HHC while remaining accessible to the population they serve. He was tremendously excited about the new health facility, which was also reusing properties that had been abandoned.

Actually I'm going up there after so you can come, [showing us photos of the area, and a booklet of photos and drawings/plans for the renovated building] This is downtown here. Basically abandoned, went out of business furniture store. This is where the pharmacy was, an alleyway and there's this building and another building behind it, and we're at 230 Maple Street. We'll be developing these two buildings. (Jay 2002)

The new building houses all of the services and administration functions of HHC with plenty of room left over for a pharmacy, dental care facility and office space for specialists. It is worth considering in more detail how this works because it is a unique arrangement.

HHC was able to convince a pharmacy to occupy the first floor of La Plaza De Salud. Jay Breines explained the pressing need for a pharmacy in downtown Holyoke:

We have a lot of low income people who need medications and they really can't easily get to the pharmacy because all the twenty odd pharmacies that used to be in downtown Holyoke, the old soda shop pharmacies all disappeared. And now you've got the CVS, Brooks, Wallgreens models and they don't want to be in downtown Holyoke because the traffic and economics doesn't fit their model.

They want to be in the suburban fringe where you can drive in and drive out.So we found that we needed a pharmacy. You can't go and get a pen to write because there's nobody to sell the sundry kind of products that a pharmacy has. So we approached the Lewis and Clark Pharmacy which is a local mom and pop pharmacy in the sense that they're in Springfield.....rather than bring in the chains, we brought in local business people who we felt would have more concern for the community. (Jay 2002)

Prior to this, there was a Rite Aid pharmacy in the same building. It had done well enough that the former owner the building tried to replace it with another pharmacy, but none of the 'suburban fringe' pharmacies were interested in locating in downtown Holyoke. Jay speculates that it is precisely because they could guarantee Lewis and Clark foot traffic that they were willing to take the risk. In the same way, HHC made room available to a dentistry practice, the first one to locate in downtown Holyoke in decades. This dental practice provides free care to HHC patients who need it.

The accessibility of services is a big issue in Holyoke because many people are without means of transportation. It is for this reason that HHC decided to make space available for specialists in private practices. Jay felt that this would address two additional barriers to care. The first problem was patients failing to show up for care.

No-shows are a big problem all because of the socio-economic status of outpatients. You know, their life problems are such that medical disease is not the ultimately the highest priority on a given day, or because they have a language problem they don't feel secure in going to a private doctor's office. You know we make the appointment and they say "yeah we'll go". It comes time to go and often they're not going to go. Or they have other problems that prevent them from going. They often don't have telephones and they can't call to cancel the appointment. Or they get there and the provider doesn't speak Spanish and they can't have a successful encounter. So for a lot of reasons, us referring to the specialists has not [historically] been successful (Jay 2002).

Jay was in negotiation with several practices at the time of this interview. The idea was that medical specialists would not only rent space from HHC but that they could also avail themselves of HHC's translation services if necessary. While this would be of benefit to both parties, this rental arrangement would provide La Plaza de Salud with additional income. Jay speculated that the development of La Plaza de Salud into a complex of businesses might change the character of downtown Holyoke.

We, if we're successful in bringing in these other tenants as we were with the pharmacy, will bring significant cash flow to the downtown economy. Not only our employees who we hire, who often come from the community. . . By bringing other practices, they'll be parking their cars downtown, coming here, driving their own staff, buying lunch, being visited by sales representatives and service people for their practices. There's going to be the spin-off of coffee shops and other little endeavors to meet basically a workday traffic that will be on the street. It'll be legal foot traffic on the street as opposed to many years ago when most of the folks that were around downtown Holyoke were unemployed or were doing things illicitly. So I think if you can put legal foot traffic on the street, you're making it safer for people moving in and out. (Jay 2002)

Collaboration with Volunteer Organizations

In addition to the interaction between HHC's expansion and the revitalization of Holyoke's commercial space, Jay described a number of efforts in which HHC interacted directly with the community. The most significant collaboration revolved around a shared recognition between HHC and citizen groups in Holyoke—among them *Nuestras Raices* and *Nueva Esperanza*—that childhood asthma was a growing problem in the community. Jay explained that this had significant consequences for the operational budget of HHC because each time an uninsured child is rushed to the emergency room for an asthma attack, it represents a one thousand dollar drain on the state free care pool, to say nothing of using up resources that could be spent elsewhere if the incidence of asthma

were brought down. HHC collaborated with these community groups to determine if there were local sources of pollution causing this elevated asthma rate. They discovered that auto-body paints contain chemicals that can trigger asthma attacks and that, throughout the town, there were a number of people engaged in automotive painting on the street where the paint fumes readily escaped into the local atmosphere. Precisely because of HHC's involvement with volunteer based community organizations, members of these organizations were able to approach the people engaged in these activities—usually done informally—and help them to see the negative consequences of what they were doing. From the perspective of this dissertation it is an important instance of formal and informal economic actors engaged in a cooperative effort.¹²⁸

New Initiatives: Health Communities Online

Jay was particularly excited about a new initiative that, at the time of the interview, was in the planning stages. Jay prefaced his description of this initiative with two observations. Holyoke, like a lot of other cities at the time, was investing in fiber optic cable. Recognizing this as an opportunity, Jay took it upon himself to contact executives from Dell computer to see if they would be willing to give computers, or lease them at low rates, to young expectant mothers in his community. At the same time he approached the city of Holyoke to ask if they would be willing to provide Internet access at reduced cost to his clientele.

¹²⁸ It is of course, unclear how successful such an effort is likely to be simply because there are other sources of air pollution affecting the Valley (but coming from far away) that also negatively impact local air quality. Jay was not claiming here that there was a quantifiable connection between point-source reduction and incidence of acute asthma. Rather he saw this as a model for collaboration between community health centers and volunteer organizations that cumulatively might transform the conditions that partially determine the health of the community.

The rationale behind this initiative was that new and young mothers could use these computers to create an online support community where advice (and perhaps other things) could be exchanged. However, Jay's deeper (?) motivation for brokering this deal was the thought that these computers might be put to use by HHC patients in other ways—that computers might help his patients with continuing education or serve as a critical input into a small business. This idea reflects Jay's commitment to fostering the connection between the health of HHC patients and their economic and social prospects in life.¹²⁹

Accountability to Community: Community Health Centers as Communal Enterprise?

Jay Breines's has a vision of the way that community health centers are (or could) be significant actors within the local economy. He sees his organization as contributing to the formal revitalization of the city of Holyoke and in active collaboration with community organizations. As much as his vision involves representing community health centers as active participants in the local economy, and not as dependent entities, he also feels that community health centers are ideally accountable to the communities in which they operate.

Jay explained that he is, ultimately, the person who makes decisions regarding purchasing, staffing and management of the health center. He has to make the same managerial decisions that administrators at an HMO like Kaiser might face.

¹²⁹ Ultimately this deal fell through but it was an interesting attempt at thinking about the way in which health care could be practiced in the context of online community. One could imagine that this collaborative approach to health care might be greeted with considerable skepticism on the part of the medical community. Jay assured us that there would be a moderator on the website but, really, it seems that he was far more interested in its potential to develop the social capital of the HHC patients in the community. His overarching concern seems to be with developing the conditions for growing social capital (Campbell 2000) or for creating the conditions for "full participation" in the networks that compose life in the community.

The important difference, from Jay's perspective, is that he has a personal relationship with the local community he is serving and the people who work for HHC.

When I recruit doctors I say "you're looking at the bureaucracy, it's right here. It's one person." Now, I don't make any decisions related to medical stuff, there's the medical director and the nurses and the doctors—we have twelve doctors—so they make their decisions. All I am concerned about is our budget at the end of the year and that, you know, "do we need more doctors or fewer doctors? More nurses or fewer nurses?"

You know "what's the best ratio of service providers that our budget can afford to provide?" And I'll say "you know that we can't afford to hire more nurses...we've got those vacancies and we're not going to fill them." Well, it's me they're going to come argue with, it's not some jerk in California that says "no more nurses this year!". . . So, I'm local, I am immediate. (Jay 2002)

In addition to the possibility of direct confrontation between Jay and the staff over the HHC management, Jay's proximity to the community HHC serves makes him more accountable than the manager of a national HMO. Continuing with this example of a potential conflict between him and his physician staff Jay points out that they are in a position to give him a vote of no confidence before the board if they feel that his management is not serving the interests of HHC or the community.

Well, a single payer health system with a non-profit structure and a community-oriented approach has a lot of screening tools built in. I can name health centers that have poorly run administrations that are going bankrupt. And that community board has to fix it by saying "you're out and someone else is coming in." So, they need the management capabilities and the role of a board of directors is to say "you're driving us in the wrong direction, either to bankruptcy or you're not providing the right kind of care we need or something." "Oh, the doctors don't like you, Jay", or whatever, and your gone. So the community owns it. The community controls through the board of directors. And it's really up to the doctors to make their case to the board that I am not doing my job. (Jay 2002)

At this point it might be objected that Jay Breines may be painting a rather generous picture of himself as an administrator or the degree of control that the community of Holyoke can exercise over HHC. This is indeed a possibility. On the other hand, even if these particular claims are overstated, Jay's conception of the community health center carries with it some important possibilities for a new politics of health care reform. Who is ultimately in charge of making economic decisions about the disposition of HHC? Is it Jay or the representatives of the community? What hangs in the balance in answering these questions is how we might theorize HHC in class terms.

HHC as the Site of a Communal Class Process: From Scarcity to Surplus

Pursuing an answer to this question makes it worthwhile to return to the class analytic dimension of the diverse economy diagram. Bearing in mind that Marx conceived of multiple class processes—feudalism, independent, capitalist and communist—each distinguished from the other by the particular condition in which surplus wealth is produced, by whom it is appropriated, and how this appropriated wealth is distributed to ensure the continuity of the class process. As I argued in chapter VI, for DeMartino (2003), it makes a difference who is involved in the process of appropriating and distributing surplus. Marxian theory suggests the possibility that non-exploitative or communal health care firms might respond to challenges, opportunities and ethical dilemmas differently than their exploitative/capitalist counterparts. Examined from the perspective of Marxian theory HHC would have to be considered a capitalist enterprise engaging wage laborers in the production of services for the poorer residents of the Holyoke and

the Pioneer Valley.¹³⁰ Jay Breines, in so far as he is the person making the decisions about how to allocate HHC revenues, who to hire, and what to procure, would appear to be occupying the position of the appropriator and the sole person in charge of making distributive decisions with respect to the reproduction of HHC. On the other hand, it might also be possible to see the board of HHC as the appropriative/distributive authority insofar as Jay is accountable to them. The board is charged with ensuring the solvency of HHC and the fulfillment of its social mandate. The fact that this board is responsive towards the community and the employees of HHC brings with it the possibility that the board is truly representative of their collective interests. Could it be that what we actually have here is an instance of a communal firm run by proxy representation? How might this affect the goals and organizational climate of HHC?

One possible answer to this question is that in this arrangement an institutional climate arises where care decisions are more highly politicized. In such an institutional context, there may be struggles over the conditions of work, the allocation of funds or whether or not HHC is meeting its mandate. In a setting such as HHC it is possible that miserliness or “scarcity” loses its status as the master signifier, its place as the central lack that conventional health care reform obsessively attempts to fill.¹³¹ HHC offers us a glimpse of health care in a context

¹³⁰ It is debatable whether HHC is actually involved in market economic activity or if it is providing its services outside of the context of a market. On the one hand, in the case of free care and care provided through Medicaid, it is possible to see that this is a non-market procurement of care by the government for qualifying indigent individuals. On the other hand, anyone can choose to become a patient at HHC, including people who have private forms of insurance. Here, it is usually both the private insurer and the individual procuring the caregiving services that may be regarded as the ultimate purchaser of care. Insofar as there are other providers available to the patient this would have to be considered an instance of market exchange.

¹³¹ In psychoanalytic parlance another name for this central lack is the symptom (Žižek 1991, Wright 1999). This is a seeming paradox since we are used to regarding a symptom as something

where hard decisions are no longer scripted in a language of self-evident scarcity. In the communally managed firm, the “hard fact of scarcity” is replaced with political struggle over how to allocate resources in such a way that care delivery is maximized.

At this point it might be objected that there is very little that separates a vision health care reform grounded in scarcity and reform conceptualized in relation to surplus. The presumed, unchanging and ever-present scarcity of the former is displaced by a vision of provisional limits, political struggle and creative responses to particular conditions. It is important to note here that “surplus” is not another term for “excess” or “abundance.” Indeed, we must insist that seeing HHC in relation to “surplus” is not a disavowal of limits. There is always a limit to surplus—ultimately there is only so much work that can be done in a day. At the same time surplus analysis connects this limit to the mutability of the conditions under which surplus is produced, appropriated and distributed, not only within HHC but in all economic processes throughout the society. There is always another way that work of care could be performed or governed, and always another way in which access could be allocated. At the same time there is a recognition that there are always other resources—gifts, volunteer labor, government support—that could be drawn upon so that HHC can discharge its duties faithfully.¹⁵²

that has a definite presence—Nora’s paralyzed arms in the case of Freud’s encounter with the “frigid” woman. As Freud himself concludes, Nora’s positive symptom is actually an expression of sexual repression—the constraints imposed upon her sexual being. Thus, the positive expression of the symptom is the manifestation of an absence. Likewise, scarcity in health care reform discourse is always linked to an excessive (symptomatic) presence: too much waste, too much demand, etc.

¹⁵² From a Marxian perspective the taxation of productive class processes (taxes levied upon a paper plant in Holyoke, for example) constitutes a distribution of surplus. The expectation in this

The surplus is a “negativity” that occupies the same space conceptually as scarcity, it is scarcity viewed from the “other side,” where ingrained miserliness gives way to politics, ethics and possibility. Surplus and scarcity are, in the Lacanian sense, two competing “fantasies” in relation to the same object, to different ways of making sense of the limits of our capacity to produce care, that have completely divergent affective and political consequences. As I discussed in chapter IV, the name that Lacanian psychoanalysis gives to the process of shifting from one “fantasy” to another is traversal (Žižek 1991, Özselçuk, and Madra 2005). It is this movement that enables a new ethically-driven process of health care reform.

HHC shifts our attention from the “reality” of scarcity to the “possibility” of the surplus. We can also see this sense of possibility in Jay’s willingness to think imaginatively—the proliferation of possibilities for collaboration and experimentation. The struggle over how to distribute surplus evokes a different sense of possibility and ethical obligation than a scarcity-based vision that calls on us to be hard-hearted in the face of grim economic “reality.” Jay Breines summed up the organizational philosophy of HHC in the following way:

A healthy community from our point of view is not just a community that receives health services, but a community that has some responsibility for maintaining health. Doctors and nurses alone cannot make people healthy; there are environmental factors. We

arrangement is that the government at different levels provides goods and services that enable the paper company to function (from roads to fiber optic cables). HHC provides a service that enables the reproduction of the labor force. Making an argument that more taxed-based financial support should be given to HHC and other similar community health centers could be understood in terms of a class politics of distribution. The radical element that Marxian theory introduces here is the link between surplus produced by productive class processes elsewhere in the economy and the necessary goods and services produced in HHC and places like it. This view recasts these organizations as productive elements of the social totality rather than dependent social service organizations.

think a healthy community is a community that has got good schools, reasonable jobs, safe streets, good health care, all the things that one would want to raise a family in a community that has those pieces. A straight physician, medical model is just a band aid, a revolving door. If our patients leave our facility and go into a hopeless environment where they know people can't get a good job, stay in school, and the streets aren't safe and so forth, we'll just keep seeing them back in. (Jay 2001)

I believe Jay is articulating an ethical commitment that completely changes the institutional mandate of community health centers. He is advocating a departure from the traditional model of the medical intervention—only dealing with people's physical health—insofar as he recognizes that HHC's duty is to engage with the total set of circumstances that affect the community. So what is at issue here is how different initiatives and structures of accountability enable HHC to faithfully discharge its ethical duty.¹³³

Like all of my informants who spoke from an institutional perspective, Jay was convinced that a universal health care system administered by the federal government would be both the most equitable and cost effective way in which to produce and allocate care. However, Jay also seems to be saying that the social relations that ensure that a community is properly cared for are something that must, of necessity, happen at the local level. Not merely suggesting that health care requires a local encounter between physician and patient; he also sees it as an encounter between caring institutions and their communities. While institutions might need support from state or federal government (larger communities), the faithful discharge of their duties happens in the context of the local community.¹³⁴

¹³³ The systemic thinking Jay articulates here is very similar to Kerry's attempts at re-conceiving her work in chapter V.

¹³⁴ While I frame Jay's argument in favor of community health centers in relation to an "ethics of the local," Jay also was capable of echoing arguments that saw community health institutions like his,

**Highland Valley: Alternative Exchange Meets Needs and Produces Well
being**

Along with other members of the CEC, I have spoken with Robert Gallant on several occasions beginning in 2002. Nancy Folbre initially put us in touch with Robert Gallant because his efforts, as the executive director of Highland Valley Elder Services (HVES), seemed to be in line with our research agenda. Robert was very generous with his time, in part because he came to recognize this congruency as well.

HVES provides adult day care services and assisted living help for people in towns throughout the Pioneer Valley. In addition HVES helps to manage two low income elder care housing complexes in Western Massachusetts: Mountain View and Washington Heights in Westfield. Like other social service agencies, HVES has been experiencing steady withdrawal of support from the state and federal government over the last twenty-five years. As Robert Gallant put it, elder services have gone from being “federally funded, state managed, and locally directed” to being “federally abandoned, state mismanaged, and locally absent” (2004). Robert sees the state’s withdrawal of support for entities like HVES as an extension of the neoliberal policies that have directed welfare reform.¹³⁵ Rather than give up or

with its smaller more transparent bureaucracies, as more efficient. As Kristoff (2005) points out, health care administrative costs per capita are three times as large in the United States as they are in Canada. In class terms minimizing the need for non-productive “oversight” workers (managerial staff) may put community health centers in a position to deliver care more efficiently.

¹³⁵ While other interviewees such as Stan and Kerry saw “capitalism” as the economic configuration that interfered with their commitment to caring, the term that Robert used was “neoliberalism.” This term is used to describe a set of practices and beliefs that occur on many different scales—from global policies that promote trade and the mobility of capital to the gradual removal of social welfare programs in the hopes that a combination of private sector charities and economic growth

“resist” this trend directly, Robert decided that perhaps it was time to return to the original goal for elder care delivery articulated in the 1960s which was a vision of progressive community control. Our goal then as now, Robert declared, is (or should be) to “put ourselves out of business” by eliminating the need for assisted living. One of the ways that Robert has done this is by developing various strategies for merging HVES with a greater “caring community”—a network of individuals, families, neighborhoods and institutions that he sees as the ideal caregivers. Robert’s efforts have been met with considerable resistance which he feels is an effect of the way social service agencies are stigmatized in the U.S.

Alternative Currency and the Community Economy to Come

Robert has a longstanding interest in alternative currencies as a way of creating local community relationships amongst neighbors and as a way of augmenting state agencies capacity of state agencies to deliver services to the elderly. At one point HVES bought up \$1500 worth of Valley Dollars, a local currency which grew out of the University of Massachusetts Women’s Network during the recession of the early 1990s. Robert’s hope was that HVES would subsidize Valley Dollars in its own small way and that Valley Dollar community residents would be willing to accept this currency in payment for volunteering to do companionship work with his elderly patients.

The whole thing fell apart because we couldn't even find enough volume or members on the Valley Trade Exchange to want to earn, to want to, be companions. Because, it's just the challenge of scale is huge and it's kind of a chicken and egg problem but you've got to get to scale which is why I am cautious. (Robert 2003)

will solve social problems. This is what Peck (2002) and Jessop (2000) refer to as the processes of neoliberal rollout and rollback.

Robert's idea takes up where Valley Dollars left off. He secured funding in the form of a small federal grant to develop an electronic currency that would be used initially by residents at the two assisted living facilities that HVES runs. He named his alternative currency "CitizenChips" to denote the fact that he wished to create a "caring community" of citizens bound together by a common currency (see Figure 7.2). The idea, at a minimum, is to validate and encourage practices of mutual aid that residents are already engaged in. Credits and debits are recorded with the use of credit card technology.



Figure 7.2: "CitizenChips"

To facilitate transactions he also developed an electronic bulletin board that would match people's needs (help with paper work, a ride to the store, companionship, etc.) with offerings from other people. He also had the idea that the currency could be used to extend this mutual aid network into the community. Robert imagined that new mapping technologies could be used to keep track of needs and offerings in the wider "caring community." One way that he hoped to counteract the bottleneck tendency was to only allow people to participate if they had both an offering and a need. Eventually he hopes to recruit businesses operating in the formal economy that would be willing to accept at least part of their payment in the form of CitizenChips.

In Robert's view, what unites members of the caring community is that every member both has something to offer as well as something they might need. An elderly resident of Washington House, one of the institutional facilities managed by HVES, might need help with grocery shopping. This same person might be able to offer a Russian immigrant help with their taxes or with reading forms from Medicare. In Robert's vision no person is entirely composed of either 'offerings' or 'needs' and it is precisely that fact that would guarantee the process of exchange and the formation of a caring community. Even storefronts that might be able to offer goods or services to the caring community also have a need to be seen as good citizens. Institutions, in Robert's view, are not defined simply by what they offer or need either.

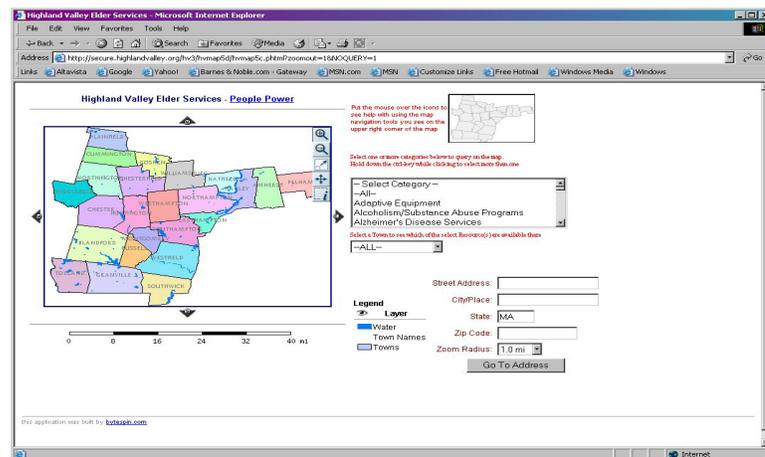


Figure 7.3: Mapping Needs and Offers in the Caring Community

Robert traveled around to different places in order to study alternative currency systems. In one interview he said that his principal inspiration for CitizenChips were the commercial barter networks in California where people in the building trades regularly exchange services with one another. A plumber might help a framer with constructing his house and expect the same in return. In Robert's view, this system works both because the services that builders exchange

are necessary and important and because members regularly come into contact with one another. The commercial barter networks are characterized by continuous exchange unlike the bottlenecks that typify a system like Valley Dollars.

At the time of this interview, Robert's vision was for a moderate sized caring community to partake in his alternative currency.

I am ready at least for this scale. A hundred merchants, five hundred card carriers and a million chips worth of transactions so that we could get the bank the two percent it needs to sustain itself. (Robert 2002)

Robert regarded the alternative currency as a way of facilitating mutual aid relationships amongst elders and between elders and the rest of the community. He hired at first one local person to recruit businesses to the caring community, and then another, but they both encountered the same reluctance on the part of the business community.

The failure (so far) of CitizenChips can be read against the failure of Valley Dollars through the philosophical opposition between content and form. Valley Dollars—borne out of the recession of the early 1990s, had plenty of subscribers that enthusiastically embraced the program but failed to circulate because there was no connection between what was needed and what was offered. This resulted in a situation where some participants whose goods and services were universally needed such as a local bakery and coffee shop accumulated too many Valley Dollars while other providers were unable to generate sufficient demand for their services. There was no effort to contain or give form to the Valley Dollar

community and the currency suffered from poor circulation as a result.¹³⁶ The failure of Robert's efforts might be seen as the opposite—while people in the business community can see the wisdom behind the form of the “caring community”, no one is willing to be an early adopter for fear of being the only one.¹³⁷ Robert's solution to this temporary set back has been to study more closely how people come to desire community in the first place which is also the study of why and how people resist belonging to or identifying with community.

The Community as Commons

Robert Gallant said that in the 1960s the idea amongst community care providers was that communities should be empowered to organize the care of their own elderly populations because they are, or ought to be, the ones most invested in it. While severe cuts in the budget for care have prompted him to pursue this strategy, he also has come to appreciate (again) the ideals that originally informed his commitment to social service work. In talking about these idea's in relation to a crisis in care delivery, Robert reflected on the difficulties in getting people to be invested in the question of how best to care as a community.

¹³⁶ Some efforts were made to correct this problem retroactively by doing a survey of Valley Dollar participants to find out their spending habits and where they would prefer to spend their Valley Dollars. Julie Graham's 1999 service learning course involved students in taking surveys of Valley Dollar members in order to see where they would like to spend their currency. The results of this survey summarized in Heyer (1999) found that most people had either never used their initial allotment of currency or had done so only once. Further, when they were asked where they would like to spend their Valley Dollars most people said that they would like to be able to purchase necessities with them—food from supermarkets and heating oil were mentioned frequently. From this Heyer concluded that most people were simply treating the Valley Dollar as a substitute for regular U.S. currency. The failure of Valley Dollars to create a community through a currency can be understood either as the failure to distinguish the Valley Dollars community from the one created by conventional exchange OR as a failure to engender a desire for this community that would make it meaningfully different.

¹³⁷ This predicament, however, did not prevent a local florist in Westfield from becoming the first business willing to accept CitizenChips.

To illustrate this difficulty, Robert gave the following example. HVES is involved not only in institutional care management but also the delivery of services to elderly people who are still living independently. One of these activities is the delivery of meals to people who are in their own residencies but could use help occasionally with obtaining basic necessities. Robert says that these types of “meals on wheels” program are facing budgetary shortfalls, reaching a crisis level in the town of Hadley in 2002 and creating a context in which a different kind of caring community might emerge.

We had a crisis around the holidays where we could no longer hire any meals on wheels drivers. We had a few people who resigned and we didn't have enough volunteers to replace them and we missed a few routes which caused a lot of pain and agonizing because the business is the delivery, not in the non-delivery. So we decided to launch a caring community coalition in Hadley around that issue. In that case the challenge was that traditionally the local players felt that "Well, gee, that's your problem" and (we argued) “well, politically, this is a community that applauds local players solving problems (Robert 2002).

Part of this resistance, Robert explained is that people are reluctant to see social service agencies as part of the community or a site of community and so the first obstacle to getting the citizens of Hadley to respond to the crisis in delivery was to get them to identify this problem as their problem. Eventually, HVES was able to identify key individuals and institutional actors that might be able to address this problem:

We asked the players in the local community to host us so that we could give our talk about all care is local and the viability of this solution only if we get local players, so we will stay in this community, not only to solve this kind of need but also in solving other kinds of needs, and this is what the caring community is all about. So sure enough after the third meeting we had participants who came from down the street, from the local Wal-Mart that was looking for something for their "good works" committee to do. Most ironically, upstairs was the local charter school who came down

stairs—their local service learning teacher, who teaches community service and their students who decided—yeah, they were in the same building. And the Hampshire education coalition whose special needs children was also involved in local service learning and finally we got a pastor from a local church who said he would beat the bushes for volunteers. (Robert 2003)

The end result of this process was that HVES was able to get enough volunteers to continue to deliver meals to Hadley residents six days a week. Nevertheless, what struck Robert the most was not that he was able to form this coalition in Hadley. Rather, his question was “Why does the “caring community” require him (or his institution) to provide this catalyzing function at all when all of the necessary resources were in place and, in some instances, residing in the same building?” Why is there so much struggle involved in mobilizing the caring community? What is the source of resistance?

Resistances to Community Economy

Robert described Hadley as a typical Yankee community that celebrates self-reliance and problem solving. I asked Robert why it is that Hadley needed to be convinced that they should work with HVES to solve this particular problem. Robert identified three sources of resistance to the caring community. The first two were interrelated: the stigma attached to “social service” agencies like HVES as “dependent” and the tendency for people to acknowledge their need (or the needs of their family) only in moments of crisis. The third source of resistance was an effect of the other two. HVES tried to surmount their stigmatization by behaving differently. However, their efforts were consistently read as “more of the same” by members of the community. In a sense, they refused to acknowledge that HVES was seeing itself as a member of the community and interacting with the community in a different way.

Robert believed that people tend to view receiving help from social service providers as a sign of personal or moral failure.

The reality is that our very agency's existence has a bad wrap because it's (funded with) federal and state dollars. Everybody thinks that if I participate I will be on the dole economically, you know, the trappings of the social service world have us feeling "if I really need it then somebody else really really needs it more than I do. . . (Robert 2003)

There is at once the fear of depriving someone who is needier than oneself and a resistance on the part of people to being seeing themselves as having "needs" in the first place. Further, Robert asserts that the current "Neoliberal" political and ideological climate exacerbates the situation. In this view welfare of any sort is conceived of as an "entitlement," a theft from the deserving and productive members of society. Robert has tried to counteract the abjection that attaches to the "social service agency" by insisting that some of the programs HVES provides are a universal entitlement—that they are simply delivering a service that tax dollars have already paid for.

We have . . . some new federal dollars targeted to family caregivers. And it's interesting because that specific initiative has an offering that says to the world if you are an elder needing care or if you are a family member giving care and needing help, call us. We have a free consultation thanks to the fact that you paid your taxes. (Robert 2003)¹³⁸

This representation of the services that HVES provides partially responds to the stigma that adheres to social service providers.

¹³⁸ Here I am reminded of Hayakawa's (1941) discussion of community A and community B. In this hypothetical scenario two different societies are faced with the challenge of providing relief to the unemployed. Community A thinks of this as a type of poverty relief which eventually engenders resentment from other members of society who regard the recipients as living off of "charity." In contrast, Community B views the same dispersal as a type of social insurance against the effects of unemployment to which every citizen is entitled. Thus there is no stigma attached to receiving it. Robert is trying to appeal to a similar logic in which at least some dimensions of HVES are seen as universally available rather than being only relevant to marginal groups.

It is at this point that this second type of resistance comes into play. Robert observes that people do not like to plan ahead in relation to making elder care decisions. As a result people only approach HVES when they are confronting a crisis.

People traditionally only come to act or care when we get really upset because or Mom has fallen or Dad has gotten worse and I don't know what to do and we're going up there to watch Dad on Sunday and we'll maneuver so we can pack his bags. (Robert 2003)

Robert says it is precisely because people only act when they or their family members are in crisis that they are prevented from imagining that they could “proactively” invest into a community that will later be in a position to support them in their time of need. Robert’s criticism here is that people only interact with his organization when they are least able to see beyond their own immediate needs and the needs of their family. In some sense this problem is the complete opposite of stigmatizing HVES as “needy.” People who come to HVES in need themselves are only capable of seeing what it offers and not imagining what they might be able to offer the institution or the community.

Thus, there is a radical inconsistency in these two resistances. The former casts social service agencies as these welfare dependent organizations—a lack or hole that needs to be filled in with money, support, etc.—while the latter sees HVES simply as a positivity—having offerings without any corresponding needs. In Robert’s vision of the caring community we learn that every member of the community has both needs and things to offer. This inconsistent vision of HVES as both “needy/dependent” and as being just ‘there’ for people to take from not only excludes HVES from being a member of the community, it points to an

insufficiency in our cultural understanding of what it means to belong in community.

HVES, in their experiments with alternative currency and collaboration with the community, is attempting to leap in place, to change its social meaning. Robert's solution is to have his institution occupy a space which becomes part of a coalition of caring institutions.

We are behaving differently and we are inviting other people to behave differently. We (as individuals) don't usually see that we are part of the solution; usually we just give some dollars to something, not giving their brainpower and their service. . . So the request is to be involved with us from the beginning as an investment, so that it's like an envelope that fits the community. But we need to recognize that this is an evolutionary thing and we have a long track record of people taking charge of their lives and communities. . . And this model of the coalition, no, it's not any of us as non-profits, it's you citizens, and you merchants, and you libraries, and you schools...We're amassing these forces that are not new forces, they are not in the business of caring just because we are inviting them but they are, hopefully through our investment and tools, they will make it more manifest and grow it. (Robert 2003)

Robert is asking us to imagine how elements of the everyday landscape—elderly people, volunteers, elder care facilities—are already part of a caring community that is yet to recognize itself. When he is given the chance to articulate this vision, which he seizes at every available opportunity, he is met with a third type of resistance—suspicion. When he explains the idea of an embracing caring community he faces a

huge challenge to peddling this kind of modality at this time is that people will say—“what I thought you were cutting?” or “Well are you generating a caring community because you are cutting?” or “Is it just an antidote to that (fiscal austerity)?” or “Is this like Reganomics?” (Robert Gallant 2003)

The very effort of HVES to position itself as something other than a dependent social service provider, to recreate itself as a site of a vital caring community, is

seen as further evidence of its abjection. All three of these resistances form a loop that ultimately contains/constrains Robert's efforts at resignifying HVES.

Robert is attempting to re-inscribe the social meaning of HVES to surmount these resistances. As of this writing, he persists in his efforts—a steadfastness that defines the meaning of an ethical act if it has any meaning at all. Robert hopes that HVES, rather than being a stigmatized social service agency or seen as a “court of last resort,” will simply be regarded as a site within the community that has both “needs” and “offer.” There are striking similarities between Robert's efforts to constitute a caring community and the potential that the CEC sees in connecting various elements of the diverse economy in a process that forms and develops community economies.¹³⁹

Cindy mentioned HVES by name during the course of her interview. She is someone who saw HVES as an abjectly dependent institution and a court of last resort. At the same time, Cindy is someone who could become a powerful ally of the caring community and HVES. For Cindy, having to rely on an organization like HVES was something that only poor people had to do. In spite of this, her solution to her mother's needs was to form a “caring community,” combining unpaid voluntary efforts of her family with a network of paid providers to produce quality care. She created a caring community around her mother that was superior, in her view, to simply placing her in a nursing home. While Cindy's mother may

¹³⁹ Robert occasionally voiced his suspicions about academia and academics in the course of our meetings with him—he insisted that he wanted neither himself nor his organization to be “studied” or “theorized.” In some ways he was reading our efforts—as activist academics—back into the dominant narrative which confines us symbolically to the ivory tower of academia. When we asked him at one point what we could do for him—to prove that we were committed to his project—he said “bring me someone who can help me promote the Caring Community.” Julie Graham was able to do just that and I think that allowed Robert to see that we were serious. In

never have needed the services of an organization like HVES, what if Cindy and others like her were to become involved in Robert's efforts, even in an advisory capacity? How might she help Robert to form a caring community?

Rio Grande Hospital: The Role of Generosity

I interviewed Norman Haug in his sister's home outside of Denver in the spring of 2005. He had made the four hour drive from Del Norte Colorado to attend a conference in downtown Denver, so my meeting him there was a turn of good fortune. We talked at the kitchen table over coffee after eating a dinner with his sister, my uncle John and Norman's three sons who were all attending Regis College nearby. Norman received his initial medical training in separate stints in South East Asia, first in the Malaysia through the Peace Corps and then later in Vietnam with the U.S. Army. This experience convinced him that achieving a basic level of care truly depended on common sense and rational planning more than the intensive application of technology.

Norman: Malaysia and Vietnam are far more organized then we are in terms of health care, even then they were. Malaysia had a really good health care system.

Stephen: What were some of the things that you noticed?

Norman: When I say that they had a really good health care system, they had good concepts and good implementation but they didn't have the kinds of scientific apparatus that we had at that time. I practiced in an eighty bed hospital in some islands that were way off the shore. I was the only physician for an island of about 20,000 people and we didn't even have electricity to use in the day time, we used the sunshine to shine into the microscope. And we had essentially no lab work but in terms of a public health sense they had clinics distributed everywhere. For instance, on these islands we had about one ten hours a way. (Norman 2005)

some sense, we were "behaving differently" as academics and we were asking for Robert to acknowledge that.

Norman said that really the treatment of illness was essentially the same in these countries as it was in the United States. Clinical assessment proceeded on the basis of physician observation and experience in these countries because they lacked the ability to do conclusive testing, but he did not regard this as a definite sign of their deficiency. Norman maintained that doctors have the same “clinical confidence” here but they are compelled to engage in conclusive testing and diagnosis in order to avoid liability. These early experiences seem to profoundly shape Norman’s beliefs that it is possible to make health care accessible to all while retaining a commitment to quality. He repeatedly expressed belief in the idea that all of the health care problems in the U.S. are resolvable and that what is required is the will to “get it done.” In his view, if less developed nations could apply rational thinking in order to create an accessible health care system it is possible in the United States also.

Norman returned to the states in the early 1960s and worked for thirteen years as an administrator at the University of Oklahoma Family Hospital where he earned a masters degree in public health. Finally, he returned to the southern Colorado town of Del Norte to open a private practice in 1981. There are 1200 people in Del Norte but his practice and the clinic he helped to construct serves a population of about 12,000 within a 75 mile radius in addition to the nearly 10,000 tourists who visit the Del Norte area each season. Norman in his twenty years of practice has assumed a remarkable range of roles—he coordinated fundraising of the construction of a new critical care facility, he is on the board of a small health maintenance organization and he is also the county coroner.

Occupying all three of these positions—physician, administrator and coroner—puts Norman in a position to be uniquely cognizant of the ethical duties

that attend caregiving. Throughout the interview he expressed his understanding of these different roles in philosophical terms, situating each in relation to generosity, dispassion towards risk, and the trust that each role requires.

Generosity, dispassion and trust seem to function in dynamic tension with one another, defining the extent of his ethical commitments—what it means to perform ones duties faithfully as a physician, administrator or coroner. These terms allow him to understand what it takes, in his words, to “get it done.” Norman, perhaps more than any other of my interviewees, understood himself as an ethical subject.

Physician and Administrator: Generosity and the General Economy of Care

Generosity was a consistent theme in my interview with Norman; he addressed the subject as it applied to a number of aspects of his professional life. First, Norman spoke about his practice of generosity as a private physician. Generosity came up again in relation to his role as a hospital administrator and the principal architect behind the construction of the new Rio Grande Hospital. Here he commented on the importance of the rural care clinics in providing care generously to the area’s poorer residents but also he was very clear that generosity on the part of the community and some state agencies played a role in the hospital’s ability to meet its social obligations.

Norman’s sister was the person who originally got me interested in his work when she told me that her brother was a country doctor who frequently engaged in “bartered exchanges.” I asked him about this, simply as a way of keeping the interview going after he finished his biographical monologue. Norman said that he “officially” did not barter but that many of his patients would bring him something that they could raise or grow—from hay to horses—as “payment” for his services. He understood this gesture not as payment but as an expression

of gratitude for care that he (and the physicians at the Rio Grande Hospital) provides for free to poor people in the community. This led me to ask him what motivated him to provide free care and how can he afford to be generous.

Stephen: I know in a hospital there is a free care pool for people who don't have insurance. How does that work on an individual--

Norman: It's an individual decision. I didn't ever turn anyone away. They pay if they could pay and didn't if they couldn't. (Norman 2005)¹⁴⁰

Norman explained that how much free care to give was a decision made by individual doctor and that other physicians might answer this question differently. I could not help but wonder if this practice of generosity was any more difficult now than it was twenty five years ago.

Stephen: Do you think it's any harder to do now than it was twenty five years ago?

Norman: No, I don't think it's any harder to do, I think it just depends on the individual physician. I think it's harder only in this sense in that, nowadays almost all physicians are in group practices run by various kinds of administrators so I think in that sense it's harder because the physician doesn't have that discretion. When you work for yourself you can do whatever you want to do. But there aren't many people who are working for themselves any more. (Norman 2005)

In Norman's view, group practices that contract with HMOs frequently find themselves having to meet the standards of certain "production models" the

¹⁴⁰ One way of understanding Norman's commitment to treat all and refuse none is in relation to the following passage from the Hippocratic Oath—"Into as many houses as I may enter, I will go for the benefit of the ill" (Von Staden 1996). This passage of the Hippocratic Oath does not categorically command that physicians treat the ill regardless of whether they can pay or not. Rather it is to be read as an admonition to subordinate all other concern during the course of treatment to care for the patient, including ones remuneration. While Badiou (2001) admires the way that the Hippocratic Oath continues to function as a truth that requires the fidelity of the physician, there is nothing in the oath itself that demands that Norman behaves the way that he does. Truly, it is Norman living out the terms of that ethical commitment that specifies the content of this principal.

eliminates physician discretion.¹⁴¹ Reading Norman's remarks here in light of Chapter V has some interesting implications from a class perspective. Norman seems to be making the argument that physicians working in a self-employed class process have greater freedom than those physicians who are contractually obligated to HMOs or are employees of firms like Kaiser. While Kaiser (and HHC) employs doctors as wage laborers, physicians affiliated with HMOs still maintain control over their work space (under a variety of class conditions). Thus, affiliation with an HMO is not exactly proletarianization but the subordination of the physician to the regulatory practices of insurers that might constrain their discretion or generosity.

While Norman saw the predominance of the HMO approach to care allocation as an impediment to physician discretion he insisted that it was still possible to be generous with one's time as a physician if one chooses to do so. In this way, Norman saw his practice of "refusing no one" not as a professional convention but as an ethical commitment on his part, a commitment that was not shared by others.

Groups have their own motivations and some are motivated towards high incomes, fancy quarters and they have to focus a lot more on money. I don't think you have to operate a group that way and we don't deal with physicians that way. (Norman 2005)

In this way, Norman opposes his ethical motivation to a set of competing values that might be dominant among other group practices.¹⁴²

¹⁴¹ Engel (2002) points out that the American Medical Association, in its earliest years, opposed the formation of a national health care system on the grounds that it would eliminate physician discretion with respect to providing charitable care.

¹⁴² Even the way Norman chose to respond to this question gives us a sense of his humility. This observation about practices that were motivated by higher incomes and "fancy quarters" was simply an observation on his part uttered without any sanctimony. While Norman was clearly a

In Norman's view hospitals, like physician practices, operate in circumstances that constrain, but do not completely eliminate, their capacity to remain in fidelity with their social mandate(s). I asked Norman what he thought of the assertion that many public and non-profit hospitals compete with one another to see who is willing to adopt the most draconian collection policies in relation to uninsured individuals (e.g. Frosh 2005). Norman responded to this question, not as a private practitioner but as the administrator of the Rio Grande Hospital:

There are hospitals here in Denver, Lutheran Hospital right over here which is a good hospital, and I am just reporting what I said in the paper the other day, but I think they have a 1 percent indigent population because they are in a suburban area and you go to other hospitals closer to downtown Denver and they have closer to 10 or 15 percent indigent people and it doesn't get spread around. I think they ought to make all of these other hospitals that are making all the money contribute to the hospitals that are taking care of the poor people. (Norman 2005)

In making this observation, Norman reiterates Sandy Eaton's complaints in a slightly different way. Hospitals that remain true to their religious or public mandate as "non-profits" run the risk of appearing unprofitable because they shoulder the bulk of the care needs of the indigent. As Sandy pointed out, when public and non-profit hospitals located in impoverished areas "partner" with more profitable hospitals they end up seeming inefficient in economic terms, creating an incentive for administrators to adopt more stringent collection policies in order to appear solvent (Frosh 2005). Norman is suggesting here that we adopt a different approach to health care accounting, one that takes geographic income discrepancies into account.

very committed Catholic his ethical commitments were subtle, private, lacking any sense of

The (Un)generous State

Norman seemed especially passionate about the guiding importance of generosity. Because of the Rio Grande's geographic location, there was a need for this generous attitude.

In our area we are in one of the poorest areas of the state, even of the country actually. So we deal with a lot of poor people and one has to take care of them. We don't turn anyone away, we take care of everybody. And we have ways to do this. We try to do this through charity and other programs but sometimes there is nothing you can do. One of the problems we have had recently, the official terms is undocumented immigrants, we are one of the main routes and about six weeks ago we had about eight of them come in. Three of them were very seriously hurt; in fact we had to send them to Denver. About three weeks ago we had twenty-two people crowded into a pickup truck, with a camper top, who'd been traveling for three days with no food and hadn't stopped for a bathroom break in eighteen hours and the driver went around a forty five mile curve on Wolf Creek road at seventy five miles an hour and all of the sudden you've got around twenty-two people, and all of these people are charity because first of all they have no money and second of all the INS, just like every other agency, they all show up and carefully wait for them to step outside the door (to arrest them) and that way they don't have to pay for anything. (Norman 2005)

The Immigration and Naturalization Service's (INS) policy plays a direct role in determining the bottom line of the Rio Grande Hospital. While Norman refuses to turn migrants away because of their inability to pay him, he certainly feels that INS policy makes his job as an administrator more difficult by making his commitment to generosity more costly. The INS, in Norman's view, should have an obligation to care for people who they will ultimately end up detaining and/or deporting rather than using their illegality as way to simply pass these costs onto the hospital.

ostentatious display.

If the INS represents one end of the spectrum in terms of the support the federal government provides to the Rio Grande, Housing and Urban Development (HUD) policy represents the other end of the spectrum. I read about Norman's efforts to secure funding for the hospital through a loan program called 242 in a local paper (Richmond 2001; Smith 2004). I asked him to explain the program, and how he went about pursuing the funds for the construction of the hospital.

Norman: Well, Housing and Urban Development has been providing money for hospitals, not giving them money but providing them with guaranteed loan for some time. But they've always worked with the smaller hospitals in New York and New Jersey.

Stephen: I wonder why there?

Norman: Well, basically, it's political. That is where the demand was and that's the areas they were familiar with. And..

Stephen: Because that's where their housing is.

Norman; And in New York, for some legal and technical reasons, it was difficult to borrow money otherwise. And so, literally, about 90 percent of their money was located in New York and New Jersey. And then I think two things happened. They had some leadership come in that thought it ought to be distributed a little more nationally and that small hospitals should be involved and then secondly they were very concerned after 9/11 they were thinking "that's where all the money is" and we need to put our money somewhere else. And so there was a program called 242 that potentially allowed small hospitals to get a guaranteed loan and tried to get interest in it. I called one person who was a mortgage broker and he talked to us and said "well, let's try it." . . . So we went through the process and they learned and we learned and we were able to get them to say that they would guarantee a ten million dollar loan and then we were able to go ahead. And we had to put up 10 percent and so we had to put up about a million and a half dollars. (Norman 2005)

Norman turned to the community to raise the 10 percent required to secure the HUD loan. It was here that the generosity of the community played a decisive role as individuals donated different amounts, from a few dollars to several thousand. Additional funding was obtained by petitioning the state for grant monies given to

areas damaged by mining. The bulk of the support, however, came from a land donation worth four hundred thousand dollars which is the site of the new hospital. The clinic opened this year and is expected to serve Del Norte, the surrounding communities and visitors. The influx of wealthy (insured) patients was part of what enabled Norman to convince HUD that the Rio Grande would remain solvent.

While the “profitability” of the Rio Grande hospital was a principal concern of the HUD (but not the INS) Medicare was interested in assuring its economic viability in yet another way. Medicare designated Rio Grande Hospital as a critical access facility. Interestingly it was this designation, along with the “export” of medical services to insured tourists that allowed Norman to make a compelling argument to HUD that the Rio Grande would remain solvent.

Norman: We had studies that showed that and so we had to show them that we could make it, that we would do enough business to make it work financially. And the reason it works, but also the reason why we had to do this was because about 70 to 75 percent of our patients are on Medicare. And we're on a cost basis. We are what is called a critical access hospital which is a government technical term for how you get paid, we get paid on a cost basis for Medicare and otherwise we would lose money. Otherwise we would lose money but we at least get the costs back and the other 25 or 30 percent we have to work out the indigent and the commercial and so on. So, in a certain sense, it's the government paying the government. (Norman 2005)

Receiving critical access status carries with it certain responsibilities. Each physician working at the clinic is expected to have 4200 patient encounters per year—assuming that one is employed at the facility full time. Most of the

physicians that work in the clinic are not full time so Norman estimates that his doctors need to see approximately 14 patients in an eight hour day.¹⁴³

There are, according to Norman, around 1000 critical access hospitals and clinics in the United States. Norman points out that these facilities frequently serve areas that are sparsely populated. Without the support of HUD and cost-based reimbursement from Medicare it is unlikely that the Rio Grande would have been built, let alone be financially viable.

Norman said that the alternative to HUD and Medicare's intervention would be to let "the market" decide hospital location. According to Norman, if "the market" was to play this role, medical facilities would tend to gravitate to the higher orders of the urban hierarchy, excluding rural communities from accessible care.

I think that the rural communities are entitled to local and regional health care just as they are to police departments and school systems. And, well, you know one of the arguments is let's centralize health care in Denver and Palm Springs and we don't need all of these other hospitals. We don't say that about the police force. And we don't say that about the school system. Well, you know, health care can be done locally and efficiently and well.
(Norman 2005)

This allows us to understand critical access facilities in a different light. They are not serving a "market" but a particular place or population that might otherwise be excluded from access. In Norman's mind this is justification enough for the state to be generous in supporting the Rio Grande—since that is what enables Norman

¹⁴³ Initially Medicare paid everyone on a cost basis and that, according to Norman, changed the way many places practiced medicine. For example, many hospitals purchased only disposable medical supplies so that each patient could be charged the maximum amount for their hospital stay. This led Medicare to abandon the practice of cost-based reimbursement in favor of capitated payments. More recently, it went back to a policy of cost-based reimbursement for qualified small hospitals (50 beds or fewer). This may reflect the fact that these hospitals are typically located in markets

and the other physicians to be generous in relation to the community.¹⁴⁴ Gifts from the community that allowed the hospital to be built, the exceptional status granted by the state, and the generosity of the practitioners are best conceived of in relation to what I will refer to as a general economy of generosity. Rather than privileging the “enterprise” as the site of accounting, these flows of generosity create a network of relations that stretch beyond the Rio Grande Hospital.

Dispassion towards Risk

A second theme that emerged during my interview with Norman was a particular dispassion towards the financial and legal risks he faced as a provider and HMO board member. In a sense, this dispassion towards risk is another facet of the general economy of generosity, as Norman sees it. In his role as a health care provider and administrator Norman understands that there are specific risks but these do not dissuade him from fulfilling his ethical mandate.

I asked Norman to comment on his involvement in managing the San Luis HMO. Norman prefaced his story by explaining the familiar way that HMOs achieve cost savings. HMOs (and most other MCO arrangements) work because preferred (or even exclusive) providers discount their services in order to have access to patients insured by the HMO. The biggest challenge in running an HMO is making sure members consult only with providers covered by the plan and that physicians refer patients to specialists within the HMO network.

We have got to keep them and then try to make sure that they get to the right hospital and the right place. Actually our physicians are quite cooperative and they are quite knowledgeable.

where it would not be possible to remain in operation if they were reimbursed on a prospective payment basis (standard fees for each element of a medical intervention).

¹⁴⁴ Norman estimates that the Rio Grande simply writes off about 45% of the services they render since experience tells them they are unlikely to collect more than 55%.

Norman said that physicians and patients occasionally game the system:

Periodically we get people that try to slip something past. Recently we had a person that was approved for an umbilical area hernia and the doctor tried to slip in taking out her big fat pad at the same time and we said “you know, we are not going to pay for that!” “You know, it wasn’t on the referral?” . . . And that is occasionally what you have to deal with, so we said “You know, we are not paying for this, this was not authorized. And we're not paying for it.” And they sometimes think they can slip that past you. You have to watch for things like that and that's not very common, it's an exception.
(Norman 2005)

Ultimately Norman felt these sorts of attempts at manipulating the system were rare. In Norman’s view neither the “moral hazard” of patients, nor the “demand inducement” of providers were the primary challenge to HMOs. Rather for Norman, the fundamental challenge facing insurers is a basic uncertainty.

Restating Reinhardt’s (2004) argument, Norman reminded me of the “cold truth” that 10 percent of the population generates 90 percent of the medical bills in the U.S. The danger that an HMO, or any other type of insurer, faces is not “exceptional” greed, but rather, the risk of having a disproportionate number of the unfortunate 10 percent enrolled as members. Norman used the following anecdote to illustrate how one individual can be the source of considerable expense.

A relatively young man, he was probably about in his late 50s and started out with pneumonia and ended up having one problem after another and despite multiple surgeries and procedures, each time we were hoping things would get better and they didn't. He spent six months in the hospital, much of it in the ICU so it’s very expensive. . . . it was not totally in our control and you can't quit in the middle of it, and sometimes we had another patient that a few months ago....I mean insurance is definitely a pool and this man happened to die but we had another fellow just a few months ago, with a somewhat similar situation and we spent three or four hundred thousand dollars and he is okay so you got to take the chance, that they are going to get better. (Norman 2005)

The point of Norman's story is that his HMO did not use the fate of the first patient to "cut their losses" in relation to the second patient. Norman seems to reflect a fundamental insight articulated by Reinhardt and many others that insurance works because it provides a solidarity context in which the fortunate 90 percent identify with and finance the care of the unfortunate 10 percent. Just as it is uncertain who among us will fall into the category of the desperately ill, the logic behind insurance against this risk is born of this same uncertainty.

It was in the context of this discussion that I asked him what he thought about national health care systems. Norman agreed with me when I suggested that the way to maximize risk distribution would be to have everyone in the same plan. A national health insurance scheme, financed through taxation, would create the largest risk pool possible on a national scale. However, he immediately added that universal access alone is not enough to solve the problem of care accessibility and quality. Even if care were reconceived as a right in this society, Norman like Sandy sees this only as the beginning of another struggle to define the content of that right.

Norman was especially critical of President Bush's endorsement of efforts to expand provisions for tax free Health Savings Accounts—a reform that Norman believes leads us in the opposite direction of health care as a universally accessible right.

I think it would work for a very small percentage of the population because most people see their health care as a necessity and they don't care what it costs at the time. They want it done, and they want it done then and they don't plan for it and they assume it's going to be alright. So I don't think it's ever going to be a big part of the health economy because people just, I mean to make that work you have to have money and most of the people don't have available money or they don't think about it that way. . . The more people you take out of the insurance system, the fewer healthy ones

you are ones you are going to have because when you're healthy you figure you can get by without this and when you are sick you sure as hell are not going to leave the health care system. (Norman 2005)

In contrast to the prevailing discourse of “personal responsibility” Norman insists that the function of insurance—in whatever form—is to serve as a way of taking onto itself the risks associated with illness and injury. For Norman, what is at stake in the current health care reform debate is not market vs. state but, rather, the individualization vs. collectivization of risk, and whether or not there will continue to be institutions that will assume collective risk in a meaningful way. If social insurance has any meaning at all, it does so because the people who run the system are indifferent/dispassionate towards risks involved. The HSA concept replaces collective with individual responsibility for the costs of accident and illness.

Dispassion towards risk surfaced at other points in the interview in a different way. I asked Norman what he thought about claims made by the Kohn et al. (1999) that there are an alarming number of medical errors in U.S. health care. I was hoping in part that he would confirm, like Sandy, that the pace of work and the case load for health care providers results in an increasing medical error rate. His response illuminated a dimension of the medical error problem that I had not previously considered.

I have mixed feelings about that, I'll tell you why, if I can take a minute or two. Part of that may have to do with pressures but part of it is how you calculate errors and what you want to call errors. Like in the nursing homes and hospitals you have what are called incident reports and I have signed off on hundreds of thousands of these things, literally thousands of them. And what are called errors are technical errors but in no way critical errors. As an example let's say you have a medicine, there's a medicine called Carafate and it has to do with the stomach. And you are supposed to give that a half hour before the meal to get its full effect and you have a full

fifteen minute leeway on either side. Let's say that the nurse forgets and she gives it ten minutes before the meal. So, she writes up a report that it's five minutes late. Now, that's a totally inconsequential error but it goes through as an error. (Norman 2005)

For Norman, these studies encourage alarmism, but don't necessarily help us to improve health care delivery. He very readily agreed with the suggestion that there are significant lapses in care delivery but insists that error rate figures, published by the Institute of Medicine and others, would have more credibility

If somehow they could distinguish between the medical error rate and the critical medical error rate, it would make more sense to me. So it really frustrates me because 95 percent of what I look at is of no consequence to anybody. (Norman 2005)

It was in this context that Norman talked with great appreciation about the work of Tom Nolan, a member of Associates in Process Improvement (API), a consulting firm located in Washington D.C. who I had the opportunity to speak with the year before. Tom's consulting firm is a leader in the field of hospital organization management. Their efforts focus on the application of organizational management techniques to the hospital workplace based on the principles developed by Edward Deming—the MIT scientist credited with the creating Total Quality Management as a concept. Deming's idea is to study the process of production itself—on assembly lines, in hospitals—to, at a minimum, describe the range of outcomes. The point of this observation is to establish a norm (the rate of production on an assembly line for instance) and then to learn the extent of deviation, identify the source of deviation and gradually work to eliminate it. Toyota was an early adopter of these techniques and applied them with great success. API is founded upon the belief that these same, simple principles could be applied to other processes.

Norman suggested to me that the application of organization management principles could perhaps be the key to understanding the difference between acceptable and critical errors in the health care field. This distinction would actually be more helpful in re-organizing health care in a way that minimizes critical errors. Norman believes this will only work if nurses, doctors and other providers are able to report errors without fear of punishment.

I think that the majority of people think that errors should be reported and dealt with but I think for the most part, for employees of the hospital and even physicians, in a non-punitive manner, and the problem is if you punish them who's going to report? But if you treat it like an error then we can move ahead. And even when I was I am acting as an insurer we have tried a new program where, when an error does occur and it was likely to maybe result in a malpractice case we to go to the injured party and apologize. The practice is to apologize and say we made an error and we'll take care of it. (Norman 2005)¹⁴⁵

Others have suggested that this policy of disclosure and apology works to minimize the expenses associated with medical malpractice. For Norman, however, contrition is necessary ultimately because the outcome of any medical intervention is uncertain. As much as he appreciates Tom's work, API exists because mistakes and errors are inevitable in the practice of medicine. For Norman it's not that medical errors are not a problem

I am not saying we shouldn't do something. I mean serious errors occur and you certainly have to do everything that you can to prevent them. And I am sure that they are not all preventable but lots of judgments have to be made everyday all day and you don't always have all the information. (Norman 2005)

For Norman what medicine requires of both insurers and providers is a willingness to intervene medically in situations where outcomes are not guaranteed. There

¹⁴⁵ This idea of apologizing to the injured party and working to correct the error immediately if possible was initially suggested by Donald Berwick (2004).

has to be a willingness on the part of providers to disregard the possibility of failure, error, in the pursuit of their tasks.

This theme of a dispassion towards risk surfaced a third time in relation to the construction of the health care clinic in Del Norte. The following month, Norman was to fly to North Dakota to give a presentation on how to secure HUD 242 grants for rural hospitals. Norman feels that it is his duty to share what he had learned about the process so that other rural hospitals and critical access facilities could get the money they need to renovate or rebuild aging facilities.

Norman provided me with a brief history of rural hospitals in the U.S. He explained that the first rural hospitals were built through a combination of federal and charitable support. A thousand rural hospitals were built with money made available by the Hillburton act of 1934. Clinical facilities were constructed alongside these hospitals with money provided by the Sears Roebuck Corporation. Most of these clinics were actually built during the 1950s. Norman felt that this history was important because it gives us some indication of what might be required to rebuild this infrastructure in the near future.

Fifty years ago people took the risk and they built these hospitals, we need to do it again. And we just need to get it done. And people will worry about, well, what's going to happen in twenty years, because these are twenty-year loans. Get the hospital built and let the person whose going to be here ten years from now worry about it. I mean that sounds callous but that's what it amounts to.

Stephen: I mean in some ways its kinds of consistent with the idea of making decisions every day without knowing the outcome. The future is unknown and that's also why we need insurance against illness.

Norman: And that's why you need to go ahead and go on with getting it done. Sometimes I have given talks and I've been in places about where they discuss, well, how are we going to pay for this because see your depreciation declines and your interest declines and we have to recognize that it will cost a little bit more in

fifteen years than it will now. Who knows what the economy is going to be like, what inflation is going to be like. . . . I mean, if inflation goes up 50 percent, it won't make any difference anyways because you are on a fixed amount, so you'll be fine. You know, if you are in a depression, well, we'll have to deal with it somehow, I don't know but the hospital is still going to be there. (Norman 2005)

Here Norman seems to be arguing that what allows for the generosity is a dispassion towards the outcome. The Rio Grande was built upon the generosity of individuals and institutions in the hope that it would be financially self-sustaining. Dispassion and generosity provide a necessary tension within which Norman constitutes the field of his ethical practice. To the extent that Norman inhabits this space of tension successfully he constitutes himself as a caring ethical subject. His status as an ethical subject is, precisely, what confers upon him a symbolic authority that one can see in his confidence and demeanor.

Symbolic Authority and Trust as a Paradoxical State

Trusting and being worthy of trust was a theme that suffused my interview with Norman. It surfaced initially in relation to his practice as a private physician. I asked Norman whether or not it was more difficult to establish a genuine trusting relationship with patients now than it was twenty-five years ago. My hope was to see whether he agreed with Groopman's (2004) assertion that the physician-patient bond is essential in medicine, whether or not it is more difficult to establish this trust now than in the past. He explained that an intimate trust is not always required nor does every patient desire such a relationship.

Norman: I think in some ways there are two kinds of people who come to physicians—some people want to get to know their physician and people who don't care and just want to fix what is wrong with them. Just like some people will only shop at the same grocery because they know where everything is and other people don't care, it's all the same to them. (Norman 2005)

Just as not everyone wants to know their physician personally; it is also true that is not necessary to know someone's life story to stitch up their arm after they cut it open on a hunting trip. With that as a caveat, Norman said that it is important to understand the desires and wishes of a patient if you are their primary care provider over time. Developing this rapport depends as much upon a patient's willingness to communicate as the communicative skill of the provider. Norman related the following anecdote to explain how patients can come to trust their physicians.

A lady who was 92, her daughter came in and she had gone to go see the doctor and we want you to take care of her, we know you and we know you will do the right thing. I've taken care of other people in the family, her two brothers, and so they developed a certain kind of confidence or preference and that's what they want. They don't want somebody new especially because they are worried that, in this case, if she was going to die I would know what to do. Some people deal with dying patients better than others and I guess that's what I do. And so as I was saying . . . I think that it is helpful for many people to have a regular physician and I think what really helps people develop a preference for a physician or some loyalty to a physician is whatever you have accomplished in times of crisis or of relative crisis. The day that you came to their house cause they broke their arm and you did well so then they are interested in seeing you again. (Norman 2005)

Žižek's (2000c) analysis of love as a paradox state seems especially applicable to Norman's thoughts here. Žižek begins by confirming the truth that one cannot simply go out and try to find love or respect—in fact such an effort usually repels people or appears ridiculous. Norman's story teaches us that you cannot make patients trust you any more than you can make yourself appear respectable or lovable. Patients can come to trust physicians because they faithfully discharge their duties in the community through time. Norman's reputation as a physician,

his authority and the trust people place in him as constituted over time in the space of the community that he serves.¹⁴⁶

In the same way Norman spoke of the need for trust to govern the relationship between him and his patients, Norman spoke of the trust that exists between himself and the state of Colorado. Though it was late in the evening when Norman began relating this story, he insisted on telling me about how medical evacuations from his area were handled to illustrate the nature of this trust.

The people in Denver know that we know how to deal with disaster and we work with them. We call them and say “Well, we need this helicopter and we need that and we need this” They know that we know what we are talking about. They see competence. We know what we are doing. We can do a lot of things as well they can, with what we have available. We don't have a lot of neurological capacity, and so we have to get them to Denver and so we do. We can tell what is going on. (Norman 2005)

Norman pointed out that trust in this matter was no small thing. A medical evacuation to Denver costs between \$17,000 and \$20,000 per trip. He could also arrange for his patients to fly to Texas by commercial jet liner. These trips could be easily arranged for between \$3,600 and \$5,600 but Norman wanted me to guess what the difference was between the commercial airliner and the helicopter trip to Denver.

Norman: The airplane wants the \$5,600 up front before they take the person. . . . So you know, when we transport these undocumented immigrants and a lot of other people (by helicopter), they don't get any money out of that, so they've got to charge three or four times as much to make it come out. But the real cost is actually, with air travel through the HMO, we can send a person to Denver by air for

¹⁴⁶ This dynamic could be seen in almost any profession. A college professor's authoritative presence is constituted through the faithful execution of duty. These efforts may or may not be recognized by peers and students. I think what distinguishes the physician and other care providers from people in other occupations are the way their duties are connected to decisions with grave consequences for the people in their care.

\$3,600 but it costs about \$17,000 to \$20,000 to call the helicopter service from Denver but they don't ever ask questions about paying right then. (Norman 2005)

The state is usually the one who picks up the cost of these medical transports which, in Norman's view, is why they had a vested interest in maintaining a rural hospital system in order to minimize these expenses.¹⁴⁷ Norman and his team are ultimately the ones entrusted with the decision of whether or not to call for medical evacuation. This is a responsibility that Norman takes very seriously so that they will continue to have access to this service should they need it.

Trust came up again as a theme in relation to death and dying. Norman claimed at one point in the interview that he had been personally present for 2,500 deaths and involved with 3,000 births. Norman described in some detail the way that he approaches the life and death aspects of his practice as a physician and, towards the end of the conversation, spent some time reflecting upon how being the county coroner invests him with a unique set of powers and responsibilities. Norman understood that trust was a function of his ability to inhabit the role of the physician—not that he was trustworthy in and of himself, but rather it was valuable for people to place this trust in him.

¹⁴⁷ Norman went onto explain that there are other reasons, from a cost control perspective, as to why rural hospitals in general, and critical access facilities in particular, are worth supporting.

The reason why this is still not unreasonable is that rural hospitals still provide the same care and they do it about four to five percent cheaper than the urban hospitals do and the ah, um, and so if you think about that and if you provide the care in that setting and you don't have to send them anywhere the government is literally saving money. The urban hospitals average about five to seven percent profit a year and the rural hospitals average about two percent. So, it's not totally a give away program. Sometimes people think "Well they are giving money away to the rural areas." Not if you look at the big picture. They are actually saving money but supporting those programs because it's keeping them out of the bigger hospitals. (Norman 2005)

In Norman's view the state is not "giving" money away to rural care facilities but is, rather, investing in a care infrastructure that is ultimately economical—when viewed from the perspective of the general economy.

Norman: I just had a lady who had a stroke, she's in her nineties and probably isn't going to do very well. And her son said "Well, you make the decisions I trust you. Well, there wasn't anything to do in that particular case and she ultimately did die but he said "I don't want to make any decisions, you make the decisions, and I trust you to make the right decisions."

Stephen: But the funny thing is that your willingness to take that on was mostly for his sake?

Norman: Right, he didn't want to feel like he was responsible.

Stephen: Yes, because who wants to be burdened with that?
(Norman 2005)

Žižek (2004b) argues that the physician is one of the few positions in the socio-symbolic order entrusted with the life or death decisions and, for this reason, the ethical dimensions of their decisions and actions are acutely clear. This, in a sense, demands of the physician both an impartiality and authoritative presence that has few parallels in other professions.

This is a particular difficult "place" to inhabit in the sense that the physician has to take the wishes of the patient and family members into account and in some instances defer to them, while at the same time she remains the "one supposed to know."¹⁴⁸ Žižek argues, following Stavrakakis (2003), that consumption, in the contemporary "post-democratic" culture, has become the singular domain of personal self-expression. According to Žižek, the space that the physician occupies as the "master" brings her into direct antagonism with this cultural norm. Whatever else we might say about someone who is bound by a sense of duty is not simply expressing a personal preference. This perhaps explains our fascination with physicians who know better than we do, a

¹⁴⁸ In so many other dimensions of economic life it is the consumer's responsibility to be well informed. Health care really is one of the few dimensions of life where the person delivering the service is also presumed to know better than we do what we need.

fascination reflected in the spate of popular TV shows about doctors and their sense of duty.¹⁴⁹ It also reflects the precarious legal position that physicians find themselves in, the continual sense of suspicion that attends their every action they pronounce the law, but they are also bound by it. While Norman understands why family members of patients wish on occasion for him to decide on their behalf, he recognizes the risks associated with assuming that duty.

And most of the time you are okay but sometimes you have to be careful because there are situations where people want the person to die usually for money. And also there's discord in the family and as we were talking about it earlier on, its easier but you can get caught because sometimes there's divisions within the family and sometimes there's a fair amount of money involved. (Norman 2005)

Norman recognizes that end of life decisions involving family members can, on occasion, bring out conflicts of interest. Like Freedman's experience this is the exception rather than the rule but it is a moment where he is called upon to keep the interests of the patient foremost in his mind, even if it means coming into conflict with family members. However, he insists that the primary challenge in providing end of life care is to approach patients and their families with a sense of steady resolve and humility, to cultivate a sort of presence that is comforting

¹⁴⁹ It is perhaps interesting to consider two contemporary broadcast programs—"Grey's Anatomy" and "House"—as cases in point. Both shows seem to combine a cultural fascination with medicine and law. "Grey's Anatomy" follows the personal and professional lives of young interns. The primary source of drama is how they mediate the tension between their professional commitments, the work space, and their intertwined and complex personal lives. The point seems to be to show how common humanity remains present in the lives of people who are, at the same time, invested with a tremendous amount of social authority and responsibility for life and death decisions. In contrast, "House" follows the life of a pain-killer addicted Dr. House and his fascination with exotic/rare conditions and illnesses. Week after week he ruthlessly pursues the truth of the patient's condition and pronounces their fate—a life that he alone can save, or a death that he pronounces with dramatic certainty. At every turn he is confronted with obstacles—the "sensitivity" of his coworkers, the bureaucratic bungling of hospital administrators whose principal concern is to make the hospital a "friendly" space, and the reluctance of patients to accept their diagnosis. The curmudgeonly House is simultaneously in the position of the "bad cop" and the skilled physician. Far from his humanity, it is his "mastery" of medical knowledge, his uncanny understanding of our

without being overbearing, authoritative yet respectful. Norman felt that he, as a physician, has exceptional skill in this area.

Norman's experience as a coroner brings another dimension of his authority to light. In death it is not really the dead person that ultimately ends up receiving the care of the physician/coroner but the people who cared for that person in life. Norman says that his approach in dealing with the relatives of the deceased was definitely something one can only learn on the job.

I had 36 year old lady who rolled her car out there. She had three kids in the car, two of her own and one that is her niece and she died there and we had to find the husband call him and take care of it right there. It's hard for people to accept that. And we had to call to get someone from the sheriff's office out there. People somehow for the most part deal with. A few don't but for the most part if you approach it carefully, then you can get through it and help people get through it. . . . It's pretty hard because you are not interested in that in medical school but a lot of physicians never learn to deal with death. You would be surprised how many people won't go to see the patient when they are dead. I always call the mortuary myself and I take care of everything myself, well not everything but the main thing. And I always go, most physicians won't go because you can do it over the telephone but I always go and try to talk to the family and I try to make it as clear and precise on the death certificate. There are some tricks to that to but you have to think about some of these things, and try and make it as easy on the family as possible. (Norman 2005)

Norman sees the level of responsibility that he takes upon himself in relation to his dead patients as something beyond what is normally done by other physicians. Norman can give this attention to his deceased in part because of his experiences as the county coroner. Attending to the details of death is no small matter because of the considerable time that is involved. The average coroner call usually takes

condition, and his indifference towards the niceties of life that makes the show far more interesting than Grey's Anatomy.

two or three hours which is a significant investment of time and precisely why some many physicians would be reluctant to take on this role.

Norman pointed out that the coroner receives a special social trust in relation to the scene of death.

The coroner is the one that decides how much he wants to do. The coroner is in charge of the scene and he has pretty broad rights. He's the only one who can get the bill fold out or go through the house; I don't need a search warrant to do anything. The sheriff has to, this lady died and this state patrol officer took her bill fold and when the captain for that area arrived he said to the patrolman "You can't touch that only the coroner can do that. You can't take anything out of somebody's pocket book!" The coroner is the only one who can arrest the sheriff so you can get into some awkward situations that way. But the coroner is in charge of the scene and you basically learn how to do it. But you always run into problems especially about possessions, you know. And in wrecks you don't know what's going to happen. (Norman 2005)

Norman went onto relate several stories about automobile wrecks where the victim had large amounts of money on their person. In his role as a coroner, he is in the position of having to make sure that the law is respected with respect to establishing the cause of death and in verifying the identity of the relatives of the deceased should they come to claim their personal effects. This frequently places Norman in a rather precarious position where his fidelity to the duties of the coroner is precisely what makes him the object of suspicion and mistrust.

This lady that died it took me forty five minutes to inventory her purse. She had about ten credit cards and all kinds of things. And we had to count all the money and it takes a long time to go through all the money. And then somebody said something about a diamond ring and I said I never saw any diamond rings. I don't know where they are and they weren't there. (Norman 2005)

When I asked Norman how he handles such a difficulty he said that a persistent attitude of humility and clarity with respect to his obligations is what is required of him. This is what allows him to bear the suspicion and accusations of theft that

accompany the role of coroner. In a sense, Norman here is describing Pascal's paradox of faith. The only way to be in this position of public trust as a physician, administrator or coroner is to act as if you already embody these qualities. Consistently maintaining this authoritative position is what, retroactively, confers authority upon the person inhabiting it. In some ways the trust that places Norman in a position of symbolic authority is the *sine qua non* of his professional practice as an ethical subject.

Conclusions from Norman

“I think that we have problems that are resolvable.” (Norman 2005)

Norman's views on the possibility for meaningful health care reform echo the sentiments of health care activist and physician Alan Sager. The dominant discourse treats health care as a series of intractable problems or contradictions to be, at best, managed. From this perspective, you cannot guarantee access without undermining efficiency and ultimately affecting the quality of care. Norman, like Alan, believes that it is possible to provide quality care for all in a way that is accessible but that what is required is the political and financial will to do so. Duty, rather than miserly administration, guides Norman's approach to health care reform. The fulfillment of duty sometimes requires generous support, sometimes it involves giving care freely and, at other times, it involves being deliberately dispassionate about the risks and costs associated with caring. In this view critical access hospitals deserve support not because they are “financially viable” but because they allow rural people access to the same level of care that their (wealthy) urban counterparts tend to enjoy. By the same reasoning, hospitals that provide care for the indigent should be supported by hospitals that operate “in the black” primarily because they serve non-indigent populations. Contextualizing care

in relation to the general economy recognizes that the “profitability” of a clinic or hospital is a function of location and the socio-economic status of their patients and not how effectively they are administered.

In a complementary fashion, Norman seems to insist that the attitude of a physician or an administrator towards risk should be one of dispassion in the face of uncertainty. Norman saw medical errors as a serious problem in health care but also one that was an unavoidable aspect of having to make decisions under pressure with imperfect information. It seemed to me that he was asking us to think of the difference between a practice of obsessively documenting medical error in the aggregate—an impulse borne of litigiousness—and examining critical mistakes in order to improve care delivery.

This same dispassion surfaced again in his role on the board of the San Luis HMO. Norman believed that it is not unreasonable for HMOs to be clear about what they will or will not pay for. However, in Norman’s view, HMOs betray their trust when they declare that a patient is terminal if there is a possibility that they might be treated effectively. Having this dispassion towards the allocation of care depends upon the willingness, at an institutional level, to bear collective risk.

Finally, in relation to trust, Norman seems to insist that his ability to embody his role as a physician, administrator or coroner depends upon his willingness to assume and perform his duties. Norman is acting as an ethical provider, board member, administrator or coroner when he is able to direct the course of his actions by balancing generosity and dispassion—locating himself as a professional within these two poles. Norman is, in this sense, a “master,” the one who is invested with trust precisely because he is “the one supposed to know.” What is interesting is not so much that physicians (and coroners) are

contemporary instances of the “master” but rather how we can see that their place in the symbolic order—their authority—is collectively authored. He recognizes that his authority and trustworthiness does not reside within him and cannot exist outside of community. His symbolic authority is externally grounded and yet it is also an effect of the humility generated by an awareness of its external origin. This understanding is perhaps what allowed Norman to be the most articulate about ethics of care.

Provisional Conclusions

Jay, Robert and Norman were each involved in administering institutions whose primary function was to serve the care needs of local communities. Each of them was cognizant of the stigma that is attached to local institutions that serve the needs of economically marginal populations. In some ways, HHC, HVES and rural hospitals like the Rio Grande embody our beliefs about health care as a social cost, as a drain on economic vitality. It is as if their existence bespeaks an illness or degeneracy in the body economic.

While all of these men seemed capable of justifying their institutions in economic terms, their actual discursive strategy for surmounting this stigma was to re-inscribe the social meaning of local care institutions. Jay did this by insisting that HHC was in a unique position to revitalize Holyoke’s downtown, if for no other reason than their mandate required them to be accessible. Robert attempted to insinuate/create for HVES a broader network of social support that could sustain his institution’s care delivery efforts. In so doing, his aim was to in effect dissolve HVES into the community economy. Ideally, HVES would just be seen as another member of the community defined both by what it needs and what it might offer. Finally, Norman, in successfully pursuing the funding for the

construction of the Rio Grande Hospital provides us with instance of how a hospital in a community setting can be the object of collective support, while at the same time providing a context for the generous/dispassionate ethical behavior of the physicians who work there.

Local Caregiving Institutions as Sites of the Community Economy

Jay, Robert and Norman give us some sense of what it means to be an ethical agent in relation to the governance of community care institutions. Their efforts to reframe the social significance of their institutions are one way of understanding how becoming-in-relation-to-duty is practiced at an institutional level. As much as these institutions are expressions of an ethical commitment—a responsiveness/accountability towards the communities they serve—they are also the sites where ethically-driven caregivers fulfill their duty. Through Norman especially, we can see how the Rio Grande or the San Louis HMO was the context for the assumption of his duties,—they were spaces in which he could embody the symbolic trust that the community placed in him.

Finally, locating these local caring institutions not in the context of the “market economy” but rather as sites within the diverse economy allows us to see both the important functions they serve in the community as well as the different forms of support they might receive from it. It is in the context of the diverse economy that we can imagine an approach to institutional governance that does not revolve singularly around miserliness.

In the concluding chapter I wish to consider in more detail how local/community- based caring institutions might provide us with a partial context for re-imagining health care reform as the development/invigoration of community economies.

CHAPTER VIII

CHANGING THE CONTEXT OF REFORM: TOWARDS A POSTFANTASMATIC POLITICS OF HEALTH CARE REFORM

Review

Chapter II described the way the conventional health care reform debate is framed as a choice between a free market and a state-based universal alternative, a debate that has been periodically restaged in the United States in these exact terms for nearly a century. The deadlocked nature of this debate and the levels of desire and anxiety that surround health care reform all suggest that it might be better understood as a fantasy in the psychoanalytic sense. The psychoanalytic conception of fantasy offers a way of understanding how the continuation of debate forms the identity of its participants and structures their “enjoyment” through this deadlock. For psychoanalysis, fantasy captures the paradox of the desiring subject—subjects remain as they are so long as the object of desire is never finally obtained. Fantasy is the process of keeping desire alive by means of a symptom that frustrates the fulfillment of desire.

From a psychoanalytic perspective these fantasies, like all fantasies, express a wish—quality, accessible, affordable care—as well as contain a symptom that forever forestalls its fulfillment. To return to an example, in the latest “free market” fantasy true competition among providers spurred on by informed consumers would transform the health care economy if only the expectations that are instilled by third-party payers could be displaced by a sense of personal responsibility. The fact that the current mixed system of health care allocation prevents most of us from exercising “personal responsibility” means that the perfect health care “free market” is a utopia. The fact that this no-where cannot be

reached only serves to make this fantasy more powerful, its absence serves as a ready explanation for the failings of the present system.

While the political debate over health care reform presents us with a deadlock, the actual trajectory of change in how health care is allocated moves the U.S. towards an ever more “mixed system” of private insurance and government directed allocation. MCOs were imagined as the “private” panacea that would contain health care costs for employers and, in some instances, states who delegated Medicaid administration to them. The idea that MCOs would “get it right” fell apart by the late 1990s. While the free-market advocates appear to be in the dominant ideological position, attempting to float increasingly radical ideas like Health Savings Accounts, an ever larger segment of the population is gaining access to care through “entitlement” programs. By the year 2014, unless things change dramatically, half the population of the United States will depend on Medicare, Medicaid or other allocation programs administered by the state.

A partial explanation for this paradox is that while the “free market” and “single payer” alternatives are ideologically divergent they share a common set of assumptions about the health care economy in general and the behaviors of patients and providers in particular. These assumptions are embodied in theories of moral hazard and demand inducement. It is because of our beliefs about patients and providers that scarcity is understood as a fundamental aspect of the care economy. Their excessive desire and demand creates scarcity. The only direction that the actual process of reform can take, as it is currently practiced by Medicare and hospital administrators, policy experts and academics is a miserly one of constraining demand and containing costs. Health care reform is a miserly discourse that inevitably produces ambivalent, frustrated subjects who are

suspicious that their own inadequate care is a function of the other's excessive demand. In other words, the very attempts to deal with scarcity engender the feeling of scarcity.

The structure of the fantasies that surround health care and its reforms has dire consequences for the untried alternative—reframing access to health care as a fundamental right to be extended to all citizens of the state (at a minimum). Given a discourse that imagines limitlessly greedy doctors and infinitely needy patients it is only logical to imagine that universal accessibility would make the problem worse—that universal accessibility will swamp the health care system with demands that cannot be satisfied. From this perspective equality of access can only mean equality of privation. Within the confines of this fantasy it becomes difficult to sustain the terms of longstanding ethical commitments that have been part of the medical tradition in the West since Hippocrates. As the social mandate of public and religious non-profit hospitals gives way to the necessity of maintaining a healthy bottom line the ethical commitments of care providers come to seem increasingly quaint, a luxury that we cannot afford. One consequence is that care becomes increasingly inaccessible to the poorest segments of U.S. society who suffer a disproportionate share of chronic and acute health problems.

I argued in chapter III that psychoanalytic theory offers a basis for an alternative intervention into the health care reform discourse, an analytic intervention that might serve to break the grip of miserliness and its unsatisfying results. The analytic approach is to treat the “knowledge” of health care reform discourse as if it were the unconscious. Wright (1999) argues that the role of the analyst is to listen for moments in the discourse when familiar terms suddenly take on an uncanny appearance. It is at these points that the analyst interrupts the

stream of discourse, creating the opportunity to insert a different interpretation of how things are or could be. The already existing discourse contains moments that might provide the basis for an alternative approach to health care reform—one that allows us to again take seriously an ethics of care. I identified three aporias in health care reform discourse that constitute, potentially, a basis for this interruption: different desires of the patient; the different relationship between care provider and patient in alternative medicine; and the different places of care that emerge when the informal economy is taken into account. While these aporias are acknowledged as fact in the dominant discourse they have yet to produce a new way of conceptualizing health care reform. Taking these different desires, relationships and places seriously both produces and calls for a different understanding of the economy of care.

Chapter III concluded with a discussion of the work of the Community Economies Collective and how insights developed in the course of their research might be applied to health care reform. The initial aim of the CEC is to produce a representation of economic space as fundamentally heterogeneous. From their perspective, multiple forms of exchange, compensation and organization are present in every economic space or sector including health care. The CEC used this insight to re-imagine the process of economic development—considering for instance, how local government, gift-giving, volunteer labor and market-oriented enterprises might be brought into a relation with one another to satisfy needs or to increase well-being. Likewise, the CEC insists that the development process can be involved in fostering businesses that are not capitalist in their organizational form but are instead organized as cooperatives, independent businesses, etc. One effect of creating a more embracing conception of economy is that it enlivens the

practice of development by involving more actors and activities in the space of economy. This more inclusive conception of economy transforms the process of development from a formulaic application of export base theory, targeted incentives, etc. to one of deliberative participation, imagination, ethics, etc.

Just as this concept of heterogeneity/articulation can be used to rethink the process of local economic development, it has implications for health care reform. There are many different processes, spaces, practices involved in the production of care. As with analysis, the first step in researching a diverse economy of care is to listen to the actors involved. What might all of the actors operating in these different locations have to say about care and its reform? Why do they do the work they do? What challenges do they face? What kinds of support might they need? If the economy of care is seen as intrinsically diverse then these questions are to be answered in a theoretically-rigorous and empirically way, rather than presumed to be answered in advance. I attempted to explore answers to these question through qualitative research represented in chapters IV through VI. In exploring the answers to these questions with interviewees from different segments of the care economy what gradually emerged was a vision of an ethical commitment to caregiving, and the conditions that either enable or undermine that commitment.

Chapter IV focused on the work of unpaid (informal) care providers. My interviewees provided me with a context for thinking about caregiving as an ethical commitment that transforms the caregiver in the process of bearing this act. Anasuya and Ashley's actions conformed to the definition of ethical. Their actions were not self interested or coerced and Ashley and Anasuya were transformed in their commission. Nevertheless, while fidelity to this ethic was based on an

Ashley and Anasuya's individual decisions, both were very clear that their ability to negotiate the affective intensity of caregiving was enabled by the support they received from their families or the broader community (emotional support, gifts, conditions of existence, etc.). What emerges from this is a vision that an individual's capacity to be a caregiver is in turn connected to the set of social conditions and relationships that support and sustain them. The diverse economy provides us with a way to formalize this connection.

In chapter IV I made sense of my encounters with independent alternative practitioners in a similar way. While the women I interviewed in this sector were producing care services for exchange, their commitment to caregiving could still be seen as an ethical act whose condition of existence was adequate remuneration. What clearly emerged in relation to each of these interviewees' stories is that their involvement in a non-exploitative independent class process is what allowed them to balance their ethical commitment to caregiving with the need to make a living, balance work and life, etc. While work-life balance, adequate rest and recognition were the principal concerns of my self-employed interviewees, chapter VI presented us with a different set of concerns for caregivers. Sandy, Stan and Cindy's caregiving work brought them into regular contact with health care's "capitalist" sector. The ethical dilemmas they confronted in this context were different from those described in the previous chapter: ethics can be concerned with relations of antagonism. Fidelity to ethics here meant commitment to a political struggle with the conditions that undermined care quality—the pace and expectations of work, falling rates of remuneration, poverty wages. What is at stake in Sandy, Stan and Cindy's struggles, as DeMartino insists, is the pursuit of justice in relation to the conditions in which surplus is produced,

appropriated and distributed. The argument I pursued here is that the aims of these various struggles was to achieve conditions of greater communality—control over the conditions of production as well as greater control and accountability in relation to the appropriation and distribution of surplus. For Stan, this meant renewing his commitment to cooperativism in his own practice; for Cindy, a transition in her household class process from capitalist/communal to independent/communal; and for Sandy it meant an ongoing struggle over the conditions of wage labor in Quincy Hospital and elsewhere.

Chapter VII provides us with a final set of insights that situate caregiving and ethics in the context of the diverse economy. Each of the men I discuss in this chapter—Jay, Robert and Norman—felt that it was critical to redefine the role of the care providing institution they managed. Rather than being seen as state-dependent social service providers they wished to resignify these institutions as part of the community that they served. These institutions both provided help—care to those that needed it—but they also received support from the community at different levels in order to do this. While locating each of these institutions as “alternative capitalist” we can see that they were being redefined in relation to processes of collaboration and support that bound them to the community economy.

Norman was particularly cognizant of the way that the Rio Grande hospital was enabled by generous support from the community (and the state), as well as being a conduit of generosity in itself. Norman located both the economy of care and his own ethical commitment in the tension between generosity and dispassion. Occupying that dynamic space was, in his view, what allowed him to be entrusted with his authority as a physician, administrator, and coroner. While

Norman recognized that caregiving requires him to embody “symbolic authority” as a physician he also recognized that his ability to do so is in part accorded to him by the community. In his own view, Norman’s ability to “get it done” is what transforms him into a servant of the community.

Chapter VII brought into focus the way in which fidelity to ethics is a process of connection, of seeking out and finding the energies that enable and sustain caregiving. The diverse economy provides us with a language with which to describe and understand this process. Ultimately what emerges from this exploration of ethics in relation to the diverse economy is the CEC’s concept of the community economy. The community economy allows us to generate an approach to health care reform that relates, potentially, to all of the different places in which care is produced, allocated and consumed and, in addition, allows us to shift from a fantasy of scarcity to a space of relative abundance and possibility. In this way, health care reform is recast as development directed by an imperative to enable sustained ethical engagement with caregiving.

From Ethics in Common to an Ethics of Commons

Our stance here involves both resisting the attractions of any positive blue print and proposing the community economy as a new and different kind of universal that might guide the process of building different economies... Unlike the structurally configured ‘economy’ with its regularities and lawful relationships, the community economy is an acknowledged space of social interdependency and self-formation. Anything but a blueprint, it is an unmapped and uncertain terrain that calls forth exploratory conversation and political/ethical acts of decision. The ‘emptiness’ of the community economy, which awaits filling up by collective actions in place is what distinguishes the project of building community economies from the related and more familiar project of economic development. (J.K. Gibson-Graham 2006, 160)

Emptiness and the Promise of Connection

In this dissertation I have situated caregiving in the space of the diverse economy and tried to show how fidelity to an ethics of care can be understood as the formation of a community economy. The diverse economy diagram represents production, exchange and remuneration as a site of formal diversity. What is evacuated from this space, according to Gibson-Graham, is a capitalocentric vision of economic space in which “capitalism” serves as the master signifier. The master signifier is replaced by the “vacuum” of heterogeneity and the possibilities of different relationships. This can be unsettling since the presence of the “the capitalist economy” as master signifier at least tells us what to submit to, what to give up or, in the case of the anti-capitalist left, what constitutes the proper object of resentment. Accommodating ourselves to emptiness and its possibilities, letting go of the certainty, requires a fundamental reconfiguration in our thinking.

Özselçuk and Madra (2005) argue that the Lacanian concept of sexuation is particularly useful in understanding this shift. They argue that the diverse economy concept supplants a masculine sexuated logic of economy with a feminine sexuated logic of economy. Sexuation is a term from psychoanalysis which describes the different ways in which the “law” can be enacted. Masculine logic situates the law in relation to an exception. Our dissatisfaction/partial satisfaction is explained in relation to the one exception that is not subject to the law. In development discourse and health care reform discourse, “capitalism/economic growth” function as the exceptional term. Scarcity constrains all other demands for care and social welfare precisely because capital is needed for capitalism (economic growth). From this perspective, as long as there is economic growth social welfare needs can be met in accordance with our priorities, but we must not

make any demand (for a welfare state, better health care benefits) that will impede economic growth.

Counter-posed to this masculine logic is a feminine one in which there is no constitutive exception—all are subject to the law, and yet no one is completely subjected. In the world of feminine sexuated logic limits remain, including limits to care, but here “scarcity,” the need for “economic growth,” no longer acts as an over-arching imperative. In my view, it is this move towards the relational possibilities (and constraints) of a feminine logic rather than the fixed miserly imperative of masculine logic that allows us to re-imagine the politics of health care reform in relation to ethical duty. Even here health care reform will continue to fail—as surely as life quits our body—but it is the nature of this failure that is transformed. Instead of failing to serve the economy as master signifier, we fail in relation to our ethical commitments.

Each of my interviewees saw their ethical fidelity to care as either enabled or undermined by the social and economic circumstances that surround their caregiving. To put in terms of sexuation—each caregiver saw themselves as partially constrained by limits and partially enabled by the circumstances in which they produced care. Anasuya and Ashley saw the critical role that support from others played in allowing them to remain faithful to the caregiving process while Irma and Ruby saw barter exchange as a way of balancing their ethical commitment to caregiving against the needs of their own livelihood. While their own self-understanding allowed them to connect an ethics of care to practices of “alternative exchange”—gift and barter—the diverse economy framework also allows us to consider how these sustaining exchanges are enabled by an independent/non-exploitative class process. It is on this basis that we might argue

for a non-capitalist health care reform, namely that non-exploitation might enable caregivers to act ethically.

Just as individual caregivers are embedded in the diverse economy and involved in producing the community economy, institutional actors could be involved as well. My interviews with Jay and Robert illustrate how institutional caregiving spaces can involve themselves with community, creating structures of accountability and mutual aid through collaboration with community organizations and the development of an alternative currency system. Could we not read Jay and Robert's efforts (and Sandy, Stan and Cindy's as well) as movement along an axiom towards a non-capitalist, specifically communal process of care? As Özselçuk and Madra (2005) might argue Jay and Robert's efforts shift the economy of care from a masculine (capitalist) logic towards an inconsistent and open feminine logic (communism).

The feminine sexuated logic of the diverse/community economy allows us to pose questions in relation to the possibility of connection or even that caregiving decisions made by the community of those who produce and consume care. We might imagine the ways in which the governance and accountability practices at Holyoke Health Center could respond to the concerns and difficulties that Stan and Sandy currently face. This turn towards greater community accountability and participation in the governance of care centers might push the production of care in a direction of greater communality. How might Ashley or Anasuya interact with Highland Valley Elder Services? Is there a way that their alternative currency could include alternative service providers like Irma or Ruby? I understand the answers we might provide to these questions as the formation of a community (ethical) economy out of the diverse economy. This process is at

once provisional and impermanent but, at the same time, allows us to re-imagine health care reform as a process of non-capitalist development, as a process of building a community economy—filling in its empty spaces.

What emerges in relation to this “negative conception” of the community economy of care is a different project of health care reform. In place of a fixed quantity of care to be allocated in accordance with a logic of scarcity we have multiple caregiving practitioners whose capacity to act ethically is defined by limits of time, energy, and available surplus; these limits, however, are not ultimately fixed. The elements of the diverse economy can be connected in ways that conserve or even expand caregiving capacity. In this way we move from caregivers united by a common ethics to an ethics of care as a metaphorical commons (Popper and Popper 1999). The diverse economy becomes a site that is generative of new possibilities, experiments and practices that involves professionals and non-professionals, patients and providers, hospitals and households, families and communities.

Fullness and the Feeling of Deflation

<i>Transactions</i>	<i>Remuneration</i>	<i>Organizational Form</i>
MARKET (Cynthia, Stan, Irma, Kerry, Ruby, Sandy, HHC, HVES, Rio Grande)	WAGE (Sandy)	CAPITALIST (Sandy)
ALTERNATIVE MARKET (Irma, HVES)	ALTERNATIVE PAID Cooperative (Stan) Self-employed (Irma, Kerry, Ruby)	ALTERNATIVE CAPITALIST State capitalist Non-profit (HVES, Rio Grande, HHC)
NON-MARKET Household flows Gifts (Rio Grande, Anasuya, Norman, Ashley, Ruby, HHC, HVES)	UNPAID Volunteer/family care (HHC, HVES, Cynthia, Anasuya, Ashley)	NON-CAPITALIST Communal (Stan) Independent (Ashley, Anasuya, Ruby, Irma, Kerry)

Figure 8.1: The Full Diverse Economy

In pursuing these tentative connections the process of representing the diverse economy of care is transformed into the project of building a community economy—an effort that begins by recognizing what is already there (Gibson-Graham 2006). To return to a question I raised in chapter IV, how can what already is be the basis for a radical reformulation of health care? This question is part of a larger question: how far have we really traveled (theoretically) by resituating health care and health care reform in the diverse economy? All of the places and actors, processes of production, exchange and support that I have described in this dissertation are part of the common, mundane, everyday landscape of caregiving. Likewise the gratitude, different forms of remuneration, volunteering, gifts, and aid from the state that enable fidelity to a caregiving ethic are equally commonplace.

As a consequence of this mundane nature, efforts at imagining the development of a community economy are frequently met with a set of familiar objections that these efforts are small scale, interstitial, and ineffectual. Orthodox Marxists encountering the work of Gibson-Graham and the CEC often dismiss it as visionless reformism. Others see in the concept of the community economy a naïve utopianism that is at odds with the “real world.” Thus there is a split in how this concept is encountered where it is simultaneously too “idealistic” and too commonplace, too “realistic.”

Gibson-Graham’s (2006) response to these charges is to point out that whatever world we might imagine, whatever social, ethical and economic relations we wish to see prevail, no matter how radical, will be constructed out of what currently is—not from nowhere but from now, here. The capacity to care, to be affected by care, to feel ethically compelled to care exists in the present. Imagining how this capacity, affective intensity and ethical sensibility is to be sustained, managed, or even enlarged (subject to development) requires us to develop another sense of the common, another means of locating the economy of care as something that is produced in-common. This process at once involves reading the present landscape of care for possibility that emerges from difference and the creation of connections amongst the elements of this diversity.

Gibson-Graham and the CEC, in their construction of the notion of the community economy have drawn significant inspiration from recent theorizations of common-resource management (Barkin 2003; Gudeman 2002; St. Martin 2001; Popper and Popper 1999). Even though some elements that might compose the community economy are not material in the way that common properties or resources are the “commons” functions, at least metaphorically, to concretize an

alternative approach to economic development. All of these authors offer us both a vision of how communities engage in the construction and management of common resources (as common property) and, furthermore, how this process of commons management constitutes them as subjects of the commons. In examining fisheries St. Martin, for example, notes how individual fishing communities, unlike bio-economists running transects through the ocean, have a much better sense of where the resources are and how to make sustainable use of their relative abundance. According to St. Martin, the fact that the dissemination of this intimate knowledge of ocean habitat is regulated by the community means that it might constitute an alternative, community-based approach to resource conservation. St. Martin argues that acknowledging the community of fishers and their commons constitutes an alternative to the prevailing policy which is a type of provisional enclosure. The common sense argument famously articulated by Hardin (1968), that common resources will always be exhausted by individuals seeking to maximize their own utility, is stood on its head. St. Martin, like Gudeman, insists that commons only fail when we fail to treat one another as communicants.

Other theorists have taken this idea of the commons and expanded it. Harvie (2004) argues for instance that scientific and other forms of academic research constitute and depend upon a body of common knowledge. This space of common knowledge is what allows for everything from the generation of common results to the independent confirmation (or elaboration) of one another's work. Currently under threat from a variety of different forces of privatization, these common-knowledge systems are a type of commons/community. I have attempted to argue here that the affective and ethical dimensions of care are

embedded in social relations. What if, like Harvie, we were to show that this most fundamental aspect of the care commons could serve as a metaphor for other types of commons?

The “diverse/community economy” might serve as a new nodal concept around which to build an alternative politics and practice of economic development or health care reform. Given that this is a novel concept, the crucial question becomes the way in which it might disseminate itself. The answer to this question is, I believe, to look for instances within the existing discourse of care where these ideas are already partially articulated. I understand this process of connecting the concept of the diverse/community economy as one of enlarging the field both where this language of difference is in-common as well as connecting it to other examples, experiments and possibilities that might relate to it.

Enlarging the Care Commons

In a talk entitled “Abundance,” delivered at the 14th Annual National Forum on Quality Improvement in Health Care in 2002, Donald Berwick attempted to fundamentally reframe how we think about health care reform.

Donald Berwick asks us to view health care delivery from a new perspective. He asks us to take off the glasses that restrict our view to only one narrow dimension: scarcity. Instead of focusing on scarcity of resources, he asks us to examine how to leverage all of the resources we already have and begin to utilize their full potential. Berwick recommends that we examine four valuable resources that are in abundant supply: patients and their families, employees, knowledge, and global brains. (Sahney 2004, 269)

To affect this shift in imagination Berwick began his talk by discussing Hawken, Lovins and Lovins’ (1999) *Natural Capitalism*. Their argument is that economic activity—conventionally defined as the combination of human capital, financial

capital and manufactured capital—is only possible because of a fourth type of capital, which they call ‘natural capital.’ The “economy,” in their view, is a small circle inside of a much larger natural rectangle. Hawken and Lovins—along with a host of others—place the annual contribution of “nature” to the global economy at \$36 trillion per annum. They argue, in a feminist fashion, that unless nature’s contribution is recognized and valued this potential abundance is wasted. Their prescription is that the conservation of resources is lean production and that the reuse of “waste” as an input into another process of production is the creation of abundance.

Berwick then asked his audience to imagine if this same reasoning could be applied to health care. This presents an immediate challenge in his view.

We are going to have to look pretty hard in health care for a sense of plenty. We’re so far down the road of an assumption of scarcity. Our lobbyists in Washington and in the state houses ask for more and more. Our providers feel drained by the demands in time and energy. Our patients and their advocates stand guard lest something be withheld. (Berwick 2004a, 278)

One untapped ‘abundance’ in health care, Berwick argues, is the knowledge of patients and their families and the unharnessed energy that they may bring to bear on the process of health care reform. Berwick’s Institute for Healthcare Improvement espouses a discourse of patient empowerment. While the language of empowerment has been historically deployed by free market reformers, it strikes me that the meaning of this term can be contested and, indeed, that it could readily be attached to the notion of the commons and the development of the community economy. For instance, Berwick (2004 b, 2004c) describes the efforts of one hospital to eliminate restrictions on patient visiting hours. Berwick points out that these restrictions were put in place by hospitals in

the 19th century as a way of excluding the families of poor patients from crowding the hospital wards. The exclusionary practices developed in the charity hospitals of the 19th century have persisted to this day. Doctors and nurses initially expressed misgivings about the idea of unlimited visiting hours—fearing that the families of patients would make additional emotional demands and slow down their work. The actual experience was that many of them reported was that family members were able to make observations about the condition of the patient over time as well as fill in critical gaps in the patient history. Further when family members were allowed to stay for longer their anxieties abated. Finally, this same hospital adopted the practice of providing families with beepers to give them “permission” to go home if they wanted to. This could be seen as an instance of turning a liability of the anxiety of patient’s families into an asset—another source of information. From the perspective of the “feminine” community economy it is a movement along an axiom towards a greater communality of production.

Berwick’s essay made me feel tremendously hopeful that the shift in thought that I am describing here is already under way in a variety of spaces. I had the opportunity to interview one of Berwick’s principal collaborators, Tom Nolan, in the spring of 2005. Tom is a chief consultant for API, a firm that provides organizational management consultations for major hospitals in the United States, the United Kingdom and in other places throughout of the globe. Applying the central insights of E.W. Deming, regarded as the principal founder of organization management theory, their goal is to both accelerate the hospital intake process, to devise means through which patients are more effectively triaged and to figure out ways to reduce both critical and non-critical error rates. The design principle at work here uses records kept by doctors, nurses and other

providers to generate an informational feed back loop. This is what Berwick refers to as the creation of “Toyotas” of health care. Just as Norman suggested, the success of this effort requires people to feel that they can report errors and other “variations” in care delivery without fearing punishment.

Allowing patients and their families and on-the-floor care providers to share information is, for Berwick, the beginnings of real health care empowerment. Connecting information generated in one social location with that produced in another is what Berwick refers to as the emergence of a global brain. It is at this point that health information technologies (HITs) play a decisive role in creating a context for continuously reducing errors and improving care quality. While some point to the costs savings that we might associate with the adoption of automated record keeping, Berwick’s vision is far more embracing—he is interested in using this flow of information in order to transform how we create/perform health care.

Currently all of these efforts are captured by a discourse of optimization, specifically applying a lean production model to care. Scarcity remains the kernel, the nodal point around which these innovative attempts at reform revolve. I asked Tom for his thoughts on this subject and he said that he felt he was not engaged in “economizing” care but rather in augmenting the capacity of hospitals to produce care. Is this not an instance of Berwick’s shift from scarcity to abundance? It seems that it would only take a slight shift in perspective to switch the meaning of “optimization” from a process of constraining demand and controlling costs to one of producing the conditions for abundance.

What if, in a very simple way, we were to think of this as the establishment of a caring commons? Sandy’s hope was that if families of patients could understand how hard nurses work they could be more sympathetic to their

perspective on reform. What we have in Berwick's example of a hospital without visiting hours is an expression of the potential of family members and professional providers working together to produce a different kind of care. What if we were to regard this not simply as collaboration between paid and unpaid providers but as part of an emergent recognition that the best care is embedded in the network of social relations? From the perspective developed in this dissertation Tom Nolan and Donald Berwick's calls to think in terms of abundance can be seen as a project of remaking oneself as caring subjects in relation to a different ethics.

How might the formation of Berwick's "global brain" be connected to the collaborative relations that are visible to us in and through the diverse economy? One way to think about this question in relation to HIT is recent efforts to develop open-source versions of HIT software. These efforts range from the development of new information technologies in Europe using LINUX to the efforts of the Veteran's Administration to make their in-house software, Veteran Health Information Systems Technology (also known as VistA), widely available at low cost (Brewin 2004). The creation of an open-source HIT has several advantages in that it will reduce costs for hospitals and physicians. At the same time, open source software's code is transparent, meaning that it can be modified or improved by end users. Finally, if it is widely adopted open source software can help patient information be more transportable. In the language of the diverse/community economy, VistA is essentially a gift that could potentially transform a number of spaces in which care is produced.

One concern that is frequently raised in relation to open source software is how its original programs can be sustained financially if its developers and programmers are unwilling to make a property-based claim on what they develop.

Jeremy Avron (2004) offered a partial solution in arguing that the U.S. health insurance industry should pay for the development and dissemination of open source HIT since they are the ones that are most likely to benefit from it as greater information increases medical knowledge, refines decision making and reduces errors.

Conclusion

Having written all of this I can still imagine someone asking me—“yes, but wouldn’t we be better off with a state administered universal health care system?” It is not difficult for me to imagine this because it is generally one of the first questions asked following presentations that I have given on this subject—usually by an earnest progressive member of the audience whose question is guided by the hope that we can, finally, have a conversation about “real health care reform.”

I myself, like Norman, Robert, Stan and my other interviewees, believe that health care should be a right; no one should be denied the care that they need. As Jay put it having a single payer system would be nice, “it would help.” The more I became involved in this project the more I came to appreciate the way that he qualified that remark; “it would help.” It would help if access to health care was conceived of as a right; but until we are all prepared as caregivers and recipients of care to guarantee the content of that right and the quality of that care, it may not make much of a difference who is paying for care or how nominally accessible it is. A government sponsored universal health care system is not going to be able to replace caring labor provided in the informal sector, it isn’t necessarily going to pay for the kinds of restorative or preventative care provided by Irma and Kerry, and it won’t necessarily have the means to identify people like Ruby and integrate them into the care sector effectively. On the other hand,

institutions like HHC, HVES and the Rio Grande Hospital—as representatives of the state (non/alternative capitalist sector) might be able to identify these actors and processes going on at the local level in the diverse economy if only we see them as existing in the same common space.

BIBLIOGRAPHY

- Ableson, Reed. 2005. "State and Employers Duel Over Health Care." *New York Times*. May 6. <http://www.nyt.com>
- Ableson, Reed. 2005. "Wal-Mart's Health Care Struggle is America's Too." *New York Times*. October 29. <http://www.nyt.com>
- Adaman, Fikeret. and Y. Madra. 2002. "Theorizing the Third Sphere: A Critique of the Persistence of the 'Economistic Fallacy'." *Journal of Economic Issues* 36(4): 1045-1078.
- Adams, Patch. 1998. *Gesundheit! Bringing Good Health to You, the Medical System and Society Through Physician Service, Complementary Therapies, Humor and Joy*. Rochester VT: Healing Arts Press.
- Adler, Nancy, T. Boyce *et al.* 1997. "Socioeconomic Inequalities in Health: No Easy Solution." In *The Social Medicine Reader*. eds. G. Henderson, N. King *et al.* 109-120. Durham NC: Duke University Press.
- Agambem, Giorgio. 2005. *State of Exception*. Chicago: University of Chicago Press.
- Allen, Scott. 2004. "Five years later, medical errors still a leading killer." *Boston Globe*. November 17. <http://www.boston.com>
- _____. 2005. "System Targets Blood-Type Mix-Ups." *Boston Globe*. February 24: A1/7.
- Alonso-Zaldivar, Ricardo. 2004. "Medicare's Troubles May Be Sleeping Giant." *Los Angeles Times*. December 20. <http://www.latimes.com>
- Alperovitz, Gar. 2004. *America Beyond Capitalism: Reclaiming Our Wealth, Our Liberty and Our Democracy*. Hoboken NJ: John Wiley & Sons.
- Althusser, Louis (1971) "Ideology and Ideological State Apparatuses (Notes Towards an Investigation)." In *Lenin and Philosophy and Other Essays*. New York: Monthly Review Press. 127-186.
- Altman, Stuart *et al.* 2003. "Escalating Health Care Spending: Is it Desirable or Inevitable?" *Health Affairs Web Exclusive*. (W3): 1-14. <http://www.healthaffairs.org>
- Amariglio, Jack and A. Callari. 1989. "Marxian Value Theory and the Problem of the Subject: The Role of Commodity Fetishism." *Rethinking Marxism*. 2(3): 31-60.

- Anders, George. 1996. *Health Against Wealth: HMOs and the Breakdown of Medical Trust*. Boston: Houghton Mifflin Company.
- Anderson, Gerald, U. Reinhardt, P. Hussey and V. Petroyan. 2003. "It's the Prices Stupid: Why the United States Is So Different From Other Countries." *Health Affairs*. 22(3): 89-105.
- Anderson, Mathew, L. Smith and V. Sidel. 2005. "What is Social Medicine?" *Monthly Review*. 56(8). <http://www.monthlyreview.org/>
- Angell, Marcia. 2004. "The Truth About Drug Companies." *New York Times Book Review*. 51(12). <http://www.nyt.com>
- Appleby, Julie. 2005. "Health Care Tab Ready to Explode." *U.S.A Today*. February 24: 1.
- Arno, Peter, C. Levine and M. Memmott. 1999. "The Economic Value of Informal Caregiving." *Health Affairs*. 18(2):182-188.
- Arrow, Kenneth. 1975. "Gifts and Exchanges." In *Altruism, Morality and Economic Theory*. ed. Edmund Phelps. New York: Russell Sage Foundation.
- _____. 2004. "New Antimalarial Drugs: Biology and Economics Meet." *Finance and Development*. 41(1): 20-21.
- Ash, Michael. 2004. "Who Lives on the Wrong Side of the Environmental Tracks? Evidence from the EPA's Risk-Screening Environmental Indicators Model." *Social Science Quarterly*. 85(2): 441-62.
- Associated Press. 2004. "Senate Backs Canada Drugs: Web Site Would Help People in State Achieve Lower Costs." *Daily Hampshire Gazette*. Friday May 21: A1/A10.
- _____. 2004. "Doctor, no! It's the Arm Not the Leg!" *Cape Cod Times*. June 22: B8.
- _____. 2005. "Study Finds Doctor's Hours Affects Risk on the Road." *New York Times*. January 13. <http://www.nyt.com>
- Avron, Jerry. 2004. *Powerful Medicines: The Benefits, Risks, and Costs of Prescription Drugs*. New York: Alfred A. Knopf.
- Badiou, Alain. 2001. *Ethics: An Essay on Understanding Evil*. London: Verso.
- Baer, Ellen, C. Fagin and S. Gordon. 1996. *The Abandonment of the Patient: The Impact of Profit Driven Health Care on the Public*. New York: Springer Publishing.
- Bailey, Steve. 2004. "Exile on Foster St." *Boston Globe*. March 10. <http://www.boston.com>

- Barer, Morris. 2002. "New Opportunities for Old Mistakes." *Health Affairs*. 21(1): 169-172.
- Barkin, D. 2003. "A Strategy to Create New Beneficiaries from World Trade" http://www.globaljusticecenter.org/papers/barkin_notes.htm#01
- Barro, Robert J. 2003. "Medicare: Forget the Drug Benefit, and Face Up to Real Reforms." *Business Week*. July 14: 28.
- Bartlett, Donald and J. Steele. 2004. "The Health of Nations." *Time*. October 24. <http://www.time.com/time/>
- Beck, Martha. 2003. "The Halo Effect." *Oprah*. December 2003: 81-84.
- Becker, Elizabeth and R. Pear. 2004. "Drug Pricing Endangers U.S.-Australia Pact." *New York Times*. Nov 17. <http://www.nyt.com>
- Beeuwkes Butin, Melinda, S. Marquis and J. Yegian. 2004. "The Role of the Individual Health Insurance Market and the Prospect for Change." *Health Affairs*. 23(6): 79-90.
- Bell, Judith and M. Standish. 2005. "Communities and Health Policy: A Pathway for Change." *Health Affairs*. 24(2): 339-342.
- Belsky, Leah, R. Lie, A. Mattoo, E. Emanuel and G. Sreenivasan. 2004. "The General Agreement on Trade in Services: Implications for Health Policymakers." *Health Affairs*. 23(3): 137-145.
- Benería, L and S. Feldman. 1992. *Unequal Burden: Economic Crises, Persistent Poverty, and Women's Work*. Boulder CO: Westview Press.
- Bennahum, David A. M.D. 1999. *Managed Care: Financial, Legal and Ethical Issues*. Cleveland OH: The Pilgrim Press.
- Bennett, Jane. 2001. "Commodity Fetishism and Commodity Enchantment." *Theory and Event*. 5(1): 35 pp. http://muse.jhu.edu/journals/theory_and_event/
- Berenson, Alex *et al.* 2004. "Despite Warnings, Drug Giant Took Long Path to Vioxx Recall." *New York Times* November 14. <http://www.nyt.com>
- Berkowitz, Bill. 2001. "Studying the Outcomes of Community Based Coalitions." *American Journal of Community Psychology*. 29(2): 213-228.
- Berwick, Donald. 2004a. *Escape Fire: Designing for the Future of Health Care*. San Francisco: Jossey-Bass.
- _____. 2004b. "Donald Berwick's Challenge: Eliminate Restrictions on Visiting Hours in the Intensive Care Unit." <http://www.ihl.org/IHI/Topics/>

- _____. 2004c. "Restricted Visiting Hours in ICUs: Time to Change." *JAMA*. 292(6): (reprint). <http://www.ihl.org/IHI/Topics/>
- Blacker, David. 1998. "Intellectuals at Work and in Power: Toward a Foucauldian Research Ethic." In *Foucault's Challenge: Discourse, Knowledge, and Power in Education*, eds. T. Popkewitz and M. Brennan, 348-367. New York: Teachers College Press.
- Blanton, Kimberly. 2004. "Employers Try Shifting Health Costs." *Boston Globe*. November 25: C1.
- Blendon, Robert, J. Benson and C. DesRoches. 2003. "Americans' Views of the Uninsured: An Era for Hybrid Proposals." *Health Affairs Web Exclusive*. (W3): 405-414. <http://www.healthaffairs.org>
- Bloom, David, D. Canning and D. Jamison. 2004. "Health, Wealth and Welfare." *Finance and Development*. 41(1): 10-15.
- Bluestone, Barry and B. Harrison. 1982. *The Deindustrialization of America*. New York: Basic Books.
- Bond Huie, Stephanie A. P.M. Krueger, *et al.* 2003. "Wealth, Race, and Mortality." *Social Science Quarterly*., 84(3): 667-684.
- Bondi, Liz. 1999. "Stages on Journeys: Some Remarks about Human Geography and Psychotherapeutic Practice." *Professional Geographer*. 51: 11-24.
- _____. 2003. "Meaning-making and Its Framing: A Response to Stuart Oliver." *Social and Cultural Geography*. 4(3): 323-327.
- Boothby, Richard. 2001. *Freud as Philosopher: Metapsychology After Lacan*. New York: Routledge.
- Bourdieu, Pierre. 1999. *Acts of Resistance: Against the Tyranny of the Market*. New York: New Press.
- Boyer, Kate. 2003. "At Work, At Home? New Geographies of Work and Caregiving under Welfare Reform in the U.S.?" *Space and Polity*. 7(10): 75-86.
- Bracher, Mark. 1993. *Lacan, Discourse, and Social Change: A Psychoanalytic Cultural Criticism*. Ithaca: Cornell University Press.
- Brady, Diane. 2003. "The Volcano Behind AETNA: Under Jack Rowe, it's a force for health-care reform." *Business Week*. June 9: 98-102.
- Brecker, Scott. 1999. *Physician's Managed Care Success Manual: Strategic Options, Alliances and Contracting Issues*. St. Louis MO: Mosby.

- Brewin, Bob. 2004. "VA Drives Open-Source Health Records Initiative." <http://govhealthit.com/article84607-11-21-04-Print#related>.
- Brewster, Devon. *et al.* 2002. "Mounting Anomalies in the Epidemiology of HIV in Africa: Cry in the Beloved Paradigm." *International Journal of STD & AIDS* (14): 144-147.
- Brown, Lawrence. 1998. "Exceptionalism as the Rule? U.S. Health Policy Innovations and Cross-National Learning. In *Healthy Markets? The New Competition in Medical Care*. ed. Mark Peterson. 353-366. Durham NC: Duke University Press.
- Brown, Patricia Leigh. 2006. "In California, New Kind of Commune for Elderly." *New York Times*. February 23. <http://www.nyt.com>
- Brown, Wendy. 2001. *Politics Out of History*. Princeton: Princeton University Press.
- Buckley, Joan. 2004. "Pharmaceutical Marketing: Time for Change." *Electronic Journal of Business Ethics and Organization Studies*. 9(2):4-11.
- Burczak, Theodore. 2004. "Focusing on Appropriative Class Justice: A Comment on DeMartino's 'Realizing Class Justice.'" *Rethinking Marxism*. 16(2): 207-209.
- Burke, Sheila, Eric Kingson and Uwe Reinhardt. 2000. *Social Security and Medicare: Individual vs. Collective Risk and Responsibility*. Washington DC: National Academy of Social Insurance.
- Bush, George. 2004a. "State of the Union Address." Washington D.C. <http://www.whitehouse.gov/2004/01/20040120-7.html>
- _____. 2004b. Second Presidential Debate. Washington University, Saint Louis Missouri. October 8.
- _____. 2004c. Third Presidential Debate. Arizona State University, . October 13.
- Butler, Judith. 1993. *Gender Trouble: Feminism and the Subversion of Identity*. New York: Routledge.
- _____. 1999. *Bodies that Matter*. New York: Routledge.
- Butler, Judith, E. Laclau and S. Žižek. 2000. *Contingency, Hegemony, Universality : Contemporary Dialogues on the Left*. London: Verso.
- Byrne, Kenneth. 2003. *A Pedagogy of Disharmony: Subjects, Economies, Desires*. E.D. Dissertation. Department of Education. University of Massachusetts, Amherst.

- Byrne, Kenneth and S. Healy. 2006. "Cooperative Subjects: Toward and Post-Fantasmatic Enjoyment of the Economy." *Rethinking Marxism*. 18(2): 241-258.
- Callahan, Daniel. 1987. *Setting Limits: Medical Goals in an Aging Society*. New York: Simon and Schuster.
- Callard, Felicity. 2003. "The Taming of Psychoanalysis in Geography." *Social & Cultural Geography*. 4(3):295-312.
- Cameron, Jenny. 2000. "Domesticating Class: Femininity, Heterosexuality and Household Politics." In *Class and Its Others*. eds. J.K. Gibson-Graham, S. Resnick and R. Wollf. 47-68. Minneapolis: University of Minnesota Press.
- Cameron, Jenny and D. Grant-Smith. 2005. "Building Citizens: Participatory Planning Practices and a Transformative Politics of Difference." *Urban Policy and Research*. 23(1): 21-36.
- Campbell, Catherine. 2000. "Social Capital and Health: Contextualizing Health Promotion within Local Community Networks." In *Social Capital: Critical Perspectives*. eds. S. Baron, J. Field and T. Schuller. 183-196. Oxford: Oxford University Press.
- Carman, James M. 1992. "Strategic Alliances Among Rural Hospitals." *Research Report. No.6* Davis CA: Center for Cooperatives, University of California.
- Chavis, David. 2001. "The Paradoxes and Promises of Community." *American Journal of Community Psychology*. 29(2): 309-321.
- Clearly Paul. 2003. "A Hospitalization From Hell: A Patient Perspective on Quality." *Annals of Internal Medicine*. 138(1): 33-40.
- Coburn, David C., C. D'Arcy and G. Torrence (eds). 1998. *Health and Canadian Society: Sociological Perspective*. Toronto: University of Toronto Press.
- Coddington, Dean C. et al. 2000. *Beyond Managed Care: How Consumers and Technology are Changing the Future of Health Care*. San Francisco: Jossey-Bass.
- Coile, Russell C. Jr. 2003. *New Century Health Care: Strategies for Providers, Purchasers and Plans*. Chicago: Health Administration Press.
- Community Economies Collective. 2001 (a). "Imagining and Enacting Noncapitalist Futures." *Socialist Review*. 28 (3/4): 93-135.
- _____. 2001 (b). "Rethinking Economy: Envisioning Alternative Regional Futures." Presentation at the Jones Library, Amherst Massachusetts, June 6.

- Connolly, Ceci and J. Weisman. 2004. "The Choice for Voters: Health Care or Tax Cuts Policy Costs Crowd Out Other Initiatives." *Washington Post*. June 28: A01.
- Cooper, Richard *et al.* 2002. "Economic and Demographic Trends Signal an Impending Physician Shortage." *Health Affairs*. 21(1): 140-154.
- Copjec, Joan. 1995. *Read My Desire: Lacan Against the Historicists*. Cambridge MA: MIT Press.
- _____. 2002. *Imagine There's No Woman: Ethics and Sublimation*. Cambridge MA: MIT Press.
- Corrigan, Janet M., A. Greiner and S.M. Erikson (eds). 2003. *Fostering Rapid Advances in Health Care: Learning from System Demonstrations*. Washington DC: National Academy Press.
- Cox, Kevin. 2004. "Globalization, the Class Relation and Democracy." *GeoJournal*. 60(1): 31-41.
- Craddock, Trent and S. Kennedy. 2005. "Analysis of International Trends in Worker Cooperatives." Unpublished paper, http://www.agr.gc.ca/rcs-src/coop/pub/pdf/aitwc_e.pdf
- Cullenberg, Stephen 1998. "Exploitation, Appropriation and Exclusion." *Rethinking Marxism*. 10(2): 66-75.
- Culyer, A.J. and A. Maynard (eds). 1997. *Being Reasonable about the Economics of Health: Selected Essays by Alan Williams*. Lyme NH: Edward Elgar.
- Cutler, David M. 2004. *Your Money or Your Life: Strong Medicine for America's Health Care System*. Oxford: Oxford University Press.
- Dalla Costa, Mariarosa. 2004. "Capitalism and Reproduction." *The Commoner*. 8 (Autumn/Winter): 1-12. <http://www.commoner.org.uk/>
- Daly, G. (1999), "Ideology and its Paradoxes: Dimensions of Fantasy and Enjoyment." *Journal of Political Ideologies*. 4(2): 219-238.
- Dao, James. 2005. "G.O.P. Pushes in States to Curb Malpractice Costs." *New York Times*. January 13. <http://www.nyt.com>
- Davenhall, David. 2004. "Harnessing Geography Improves Outcomes." *ESRI Online*. <http://www.esri.com/news/arcuser/0404/spring2004.htm>
- Dean, Howard. 2004. "The First Americans are Last in Health Care." <http://www.YubaNet.com>

- Deber, Raisa. 2000. "Getting What We Pay for: Myths and Realities about Financing Canada's Health Care System." A background paper prepared for the Dialogue on Health Reform: Sustaining Confidence in Canada's Health Care System. April 11.
- Deleuze, Felix and G. Guatari. 1987. *Thousand Plateaus: Capitalism and Schizophrenia*. Minneapolis: University of Minnesota Press.
- DeMartino, George. 2003. "Realizing Class Justice." *Rethinking Marxism*. 15(1): 1-32.
- Derrida, Jacques. (1978). *Writing and Difference*. Chicago: University of Chicago Press.
- _____. 1994. *Specters of Marx*. New York: Routledge.
- _____. 1996. "Remarks on deconstruction and pragmatism." In *Deconstruction and Pragmatism*, S. Critchley, J. Derrida, E. Laclau, and R. Rorty, ed. C. Mouffe. 77-88. London: Routledge.
- _____. 1998. *Resistances of Psychoanalysis*. Stanford CA: Stanford University Press.
- Diskin, Jonathan and B. Sandler. 1993. "Essentialism and the Economy in the Post Marxist Imaginary: Reopening The Sutures." *Rethinking Marxism*. 6(3): 28-48.
- District XI Area Agency on Aging, Inc. 2004. "Elder Caregiving." <http://www.distxiaaoa.com/caregiver/elderlycaregiving.htm>.
- Dobson, John. 2004. "Method to Their Madness: Dispelling the Myth of Economic Rationality as a Behavioral Ideal." *Electronic Journal of Business Ethics and Organization Studies*. 9(2): 11pp.
- Doel, Marcus. 1994. "Deconstruction on the Move: From Libidinal Economy to Liminal Materialism." *Environment and Planning A*. (26): 1041-1059.
- Doel, Marcus and J. Segrott. 2004. "Materializing Complementary and Alternative Medicine: Aromatherapy, Chiropractic and Chinese Herbal Medicine in the UK." *Geoforum*. (35): 727-738.
- Donelan, Karen, C. Hill, *et al.* 2002. "Challenge to Care: Informal Caregivers In a Changing Health System." *Health Affairs*. 21(4): 222-231.
- Dranove, David 1998. "Medicaid Dependent Hospitals and Their Patients: How Have they Fared?" *Health Services Research*. 33(2): 163-186.
- _____. 1999. *How Hospitals Survived: Competition and the American Hospital*. Washington DC: AEI Press.

- _____. 2000. *The Economics Evolution of American Health Care: from Marcus Welby to Managed Care*. Princeton NJ: Princeton University Press.
- _____. 2003. *What's Your Life Worth? Health Care Rationing... Who Lives? Who Dies? And Who Decides?* Up Saddle River NJ: Times Prentice Hall.
- Dukakis, Michael. 2004. "The Uninsured: 44 Million and Counting." A talk given at The Center for Public Policy and Administration, University of Massachusetts Amherst, September 23.
- Eberstadt, Nicholas and S. Satel. 2004. "Health, Inequality and the Scholars." *The Public Interest*. No. 157 (Fall): 100-119.
- Eichner, June and B. Vladeck. 2005. "Medicare as a Catalyst for Reducing Health Disparities." *Health Affairs*. 24(2): 365-375.
- Engel, Johnathan. 2002. *Doctors and Reformers: Discussion and Debate over Health Policy 1925-1950*. Columbia: University of South Carolina Press.
- Ehrenreich, Barbara. 2004. "Gouging the Poor." *The Progressive*. February 4.
- Etzioni, Amitai. 1991. "Health Care Rationing: A Critical Evaluation." *Health Affairs*. 10(2): 88-95.
- Fevre, Ralph. 2000. "Socializing Social Capital: Identity, the Transition to Work, and Economic Development." In *Social Capital: Critical Perspectives*. eds. S. Baron, J. Field and T. Schuller. 94-110. (Oxford: Oxford University Press)
- Fink, Bruce. 1995. *The Lacanian Subject: Between Language and Jouissance*. Princeton NJ: Princeton University Press.
- Finkelstein, Eric *et al.* 2003. "National Medical Expenditures Attributable to Overweight and Obesity: How Much , and Who's Paying?" *Health Affairs*. 22(1): 219-226.
- Finkler, Merton. 2002. "Whack a Mole and Other Approaches to Health Care Cost Containment." Lawrence University Science Hall Colloquium, Appleton Wisconsin, April 18.
- Folayemi, Babatunde. 2001. "Case Story #1: Building the Grassroots Coalition." *American Journal of Community Psychology*. 29(2): 193-203.
- Folbre, Nancy. 2001. *The Invisible Heart: Economics and Family Values*. New York: The New Press.
- Fong, Tony. 2005. "Health Care Consumers Show Little Interest in Chargemaster Despite Growing Movement to Mandate Price Disclosure." *Modern Health Care*. 35(13): 6-9.

- Foucault, Michel. 1977. *Discipline and Punish: The Birth of the Prison*. New York: Pantheon Books.
- _____. 1994. *Foucault: Ethics, Subjectivity and Truth*. New York: New Press.
- Fox, Daniel. 2005. "Evidence of Evidence-Based Health Policy: The Politics of Systematic Reviews in Coverage Decisions." *Health Affairs*. 24(1): 114-122.
- Fraad, Harriet, S. Resnick and R. Wolff. 1994. *Bringing It All Back Home: Class, Gender and Power in the Modern Household*. London: Pluto Press.
- Fraad-Wolff, Max. "A Theory of the Subsumed Class Struggle: A Look at the Growth of Merchanting in Finance Since WWII." A talk given at the Association for Social Analysis Annual Summer Conference, Hancock Massachusetts, July 26, 2003.
- Francisco, Vincent, S. Fawcett, *et al.* 2001. "Using Internet-based Resources to Build Community Capacity: The Community Tool Box." *American Journal of Community Psychology*. 29(2): 293-301.
- Fraser, Nancy. 1985. "Michel Foucault: A 'Young Conservative'?" *Ethics*. 96 (Oct): 165-184.
- Freedman, Benajmin. 1999. *Duty and Healing: Foundations of a Jewish Bioethics*. New York: Routledge.
- Freie, John. 1998. *Counterfeit Community: The Exploitation of Our Longings for Connectedness*. Lanham MD: Rowman & Littlefield Publishers, Inc.
- Freud, Sigmund. 1938. *The Basic Writings of Sigmund Freud*. (New York: The Modern World).y
- _____. 1939. *Moses and Monotheism*. (New York: Vintage Books).
- _____. 1999. *Civilization and Its Discontents*. (New York: Dover).
- Freudenheim, Milt. 2003. "Employees Pay 48% More for Company Health Plans." *New York Times*, September 10. <http://www.nyt.com>
- Frosh, Dan. 2005. "When Getting Sick Means Going Broke: Your Money or Your Life." *The Nation*. 280(7): 11-14.
- Fuchs, Victor. 1974. *Who Shall Live? Health, Economics and Social Choice*. New York: Basic Books.
- Fuhrmans, Vanessa. 2005. "Radical Surgery -- One Cure for High Health Costs: In-House Clinics at Companies; Wisconsin Firm Saves Money By Hiring Its Own Doctors; Patients Get More Time; A Hard Sell for Some Workers." *The Wall Street Journal*. CCXLV 30 (Feb 11): 1/A8.

- Gabel, Jon, A. LoSasso and T. Rice. 2002. "Consumer Driven Health Plans: Are They More Than Talk Now." *Health Affairs Web Exclusive*. (W2): 395-407. <http://www.healthaffairs.org>
- Gatrell, Anthony C. 2002. *Geographies of Health*. London: Blackwell.
- Gawande, Atul. 2004. "The Bell Curve: What Happens When Patients Find Out How Good Their Doctor's Really Are?" *The New Yorker*. December 6: 82-91.
- Gearan, Anne. 2004. "High Court Shields HMOs." *Cape Cod Times*. June 22: A1/A6.
- Gingerich, Ray and B. Busching. 2000. "New Approaches to Power in Grassroots Coalition Building: A Case Study of Common Ground." In *Feminist Approaches to Social Movement, Community and Power, Volume One: Conscious Acts and the Politics of Social Change*. eds. R. Teske and M. Tétreault. Colombia: University of South Carolina Press.
- Gibson-Graham, J.K. 1996. *The End of Capitalism (as we knew it): A Feminist Critique of Political Economy*. London: Blackwell.
- _____. 2003a. "An Ethics of the Local." *Rethinking Marxism*. 15(1): 49-79.
- _____. 2003b. "Enabling Ethical Economies: Cooperativism and Class." *Critical Sociology* 29(2): 1-39.
- _____. 2003c. "Feminising the Economy: Metaphors, Strategies, Politics." *Gender, Place and Culture*. 10(2): 145-157.
- _____. 2006. *Postcapitalist Politics*. Minneapolis: University of Minnesota Press.
- Gibson, Kathy and J. Cameron. 2001. "Transforming Communities: Towards a Research Agenda." *Urban Policy and Research*. 19(1): 7-24.
- Gibson-Graham, J.K., S. Resnick and R. Wolff. 2001. *Representing Class: Essays in Postmodern Marxism*. Durham NC: Duke University Press.
- Gilligan, Carol. 1982. *In a Different Voice: Psychological Theory and Women's Development*. Cambridge MA: Harvard University Press.
- Gisselquist, David *et al.* 2002. "HIV Infection in Sub-Saharan Africa not Explained by Sexual or Vertical Transmission." *International Journal of STD & AIDs*. (13): 657-666.
- _____. 2003. "Let it be Sexual: How Health Care Transmission of AIDS in African was Ignored." *International Journal STD & AIDs*. (14): 148-161.

- Glasser, Ruth and J. Brecher. 2003. *We are the Roots: The Organizational Culture of a Home Care Cooperative*. Davis CA: Center for Cooperatives, University of California.
- Gleckman, Howard. 2004. "Your New Health Plan: Health Plan." *Business Week*. November 8: 88-98.
- Glynos, Jason. 2000. "Thinking the Ethics of the Political in the Context of a Postfoundational World: From an Ethics of Desire to an Ethics of Drive." *Theory and Event* 4(4): 14 pps.
- Glynos, Jason. 2001. "The Grip of Ideology: a Lacanian Approach to the Theory of Ideology." *Journal of Political Ideologies*. 6(2): 191-214.
- Goldsmith, Jeff. 2002. "Integrating Care: A Talk With Kaiser Permanente's David Lawrence." *Health Affairs*. 21(1): 39-48.
- Goldstein, Raymond *et al.* . 2001. "Harry and Louise and Health Care Reform: Romancing Public Opinion." *Journal of Health Politics, Policy and Law*. 26(6): 1325-1352.
- Goodchild, Michael *et al.* 2000. "Towards a Spatially Integrated Social Science." *International Regional Science Review*. 23(2): 139-159.
- Gottschalk, Marie. 2000. *The Shadow Welfare State: Labor, Business, and the Politics of Health Care in the United States*. Ithaca: ILR Press.
- _____. 2000b. "It's the Health-Care Costs, Stupid!: Ideas, Institutions, and the Politics of Organized Labor and Health Policy in the United States." *Studies in American Political Development*. 14(2): 234-252.
- Goyer, Claire, C. Mitchell *et al.* 2004. "Local Health Centers Offer Solution to Health-care Crisis." *Cape Cod Times*. August 22: E3.
- Grady, Denise. 2004. "Trying to Avoid the 2nd Caesarian, Many Find the Choice Isn't Theirs." *New York Times*. November 29.
- Graham, Julie S. Healy and K. Byrne. 2002. "Constructing the Community Economy: Civic Professionalism and the Politics of Sustainable Regions." *Journal of Appalachian Studies*. 8(1): 50-61
- Granich, Reuben and J. Mermin. 2003. *HIV Healthy and Your Community: A Guide for Action*. Berkeley CA: Hesperian Foundation.
- Gray, Deborah (ed). 1993. *Cooperative Solutions to Rural Health Care Problems: Emergency Medical Service*. Conference Proceedings, Center for Cooperatives, University of California at Davis.

- Greenberger, Scott. 2005. "House Approves Healthcare Overhaul: Tax at Odds with Plans by Romney, Travaglini." *The Boston Globe*. November 4. <http://www.boston.com>
- Groopman, Jerome. 2004. *The Anatomy of Hope: How People Prevail in the Face of Illness*. Random House: New York.
- Gruber, J., J. Kim and D. Mayzlin. 1998. "Physician Fees and Procedure Intensity: The Case of Cesarean Delivery." Working paper 6744, National Bureau of Economic Research.
- Grumbach, Kevin. 2002. "Ramifications of Specialty-Dominated Medicine." *Health Affairs*. 21(1): 155-157.
- Gudeman, Stephen and A. Rivera. 1990. *Conversations in Colombia: The Domestic Economy in Life and Text*. Cambridge MA: Cambridge University press.
- _____. 2001. *The Anthropology of Economy: Community, Market, and Culture*. Malden MA: Blackwell.
- Guevara, Che. 2005. "On Revolutionary Medicine." *Monthly Review*. 56(8). <http://www.monthlyreview.org/>
- Gunn, C. and H.D. Gunn. 1991. *Reclaiming Capital: Democratic Initiatives and Community Development*. Ithaca: Cornell University Press.
- Gunn, Christopher. 2004. *Third-Sector Development: Making Up for the Market*. Ithaca: Cornell University Press.
- Gusmano, Michael, G. Fairbrother and H. Park. 2002. "Exploring the Limits of the Safety Net: Community Health Centers and Care for the Uninsured." *Health Affairs*. 21(6): 188-194.
- Hadley, Jack and J. Holahan. 2003. "How Much Medical Care Do the Uninsured Use, and Who Pays for It?" *Health Affairs*. 22(1): 66-81.
- Hamilton, William L. 2005. "The New Nursing Home: Emphasis on Home." *New York Times*. April 23. <http://www.nyt.com>
- Harari, Roberto. 2001. *Lacan's Seminar on 'Anxiety'*. New York: Other Press.
- Hardin, Garrett. 1968. "The Tragedy of the Commons." In *Managing the Commons*. (San Francisco: W.H. Freeman and Company): 16-30.
- Hardt, Michael and A. Negri. 2000. *Empire*. Cambridge MA: Harvard University Press.
- Harris, Gardiner. 2004. "In American Health Care, Drug Shortages Are Chronic." *New York Times*. October 31. <http://www.nyt.com>

- Harvie, David. 2004. "Commons and Communities in the University: Some Notes and Some Examples." 8 (Autumn/Winter).
<http://www.commoner.org.uk/08harvie.pdf>
- Hawken, Paul, A Lovins and L. Lovins. 1999. *Natural Capitalism: Creating the Next Industrial Revolution*. Boston: Little and Brown Co.
- Hayakawa, Samuel. 1941. *Language in Action*. New York: Harcourt, Brace and Company.
- Healy, Beth. 2004. "Masachusetts Scariest IT Project." *Boston Globe* April 5: C1/4.
- Henderson, Gail, N. King *et al.* 1997. *The Social Medicine Reader*. Durham NC: Duke University Press.
- Herbert, Bob. 2005. "A Gift for the Drug Makers." *New York Times*. January 14.
<http://www.nyt.com>
- Herbert, Steve. 2005. "The Trapdoor of Community." *Annals of the Association of American Geographers*. 95(4): 850-865.
- Herzlinger, Regina. E.1997. *Market Driven Health Care: Who Wins, Who Loses in the Transformation of America's Largest Service Industry*. Cambridge MA: Perseus Books.
- Hetch, Robert, A. Batson, and L. Brenzel. 2004. "Making Health Care Accountable. Why Performance-based Funding of Health Services in Developing Countries is Getting More Attention." *Finance and Development*. 41(1):16-19.
- Heyer, Rose. 1999. "Valley Trade Connection: A Class Analysis." Unpublished paper, Department of Geosciences, University of Massachusetts, Amherst.
- Himmelman, Arthur, D. Johnson *et al.* 2001. "Roundtable Discussion and Final Comments." *American Journal of Community Psychology*. 29(2): 205-211.
- Himmelstein, David *et al.*2003. "Proposal of the Physicians Working for Single-Payer National Health Insurance." *Journal of the American Medical Association*. 290(6): 798-805.
- Holahan, John, A. Weil and J. Wiener. 2003. "Which Way for Federalism and Health Policy?" *Health Affairs Web Exclusive*. (W3): 317-333.
- Holloway, John. 2002. "Twelve Theses on Changing the World Without Taking Power." *The Commoner*. 4 (May): 1-6.
- Hunter, David. 1997. *Desparately Seeking Solutions: Rationing Health Care*. London: Longman.

- Hussey, Peter, *et al.* 2004. "How Does the Quality of Care Compare in Five Countries?" *Health Affairs*. 23(3): 89-99.
- Illich, Ivan. 1984. *Medical Nemesis: The Expropriation of Health*. New York: Pantheon Books.
- Institute for Healthcare Improvement. 2004. *The Courage to Act on What If: 2004 Progress Report*. (Boston: Institute for Health Care Improvement).
- _____. 2004. "A Challenge Accepted: Open Visiting Hours in the ICU at Geisinger." <http://www.ihl.org/IHI/Topics/>
- Institute for the Future. 2000. *Health and Health Care 2010: The Forecast, The Challenge*. San Francisco: Jossey-Bass Publishers.
- Ironmonger, D. 1996. "Counting Outputs, Capital Inputs and Caring Labor: Estimating Gross Household Product." *Feminist Economics*. 2(3): 37-64.
- Jessop, Bob. 2000. "The Crisis of the National Spatio-Temporal Fix and the Tendential Ecological Dominance of Globalizing Capital." *International Journal of Urban and Regional Research*. 24(2): 324-360.
- Jhally, Sut. 1997. "Stuart Hall: Race, the Floating Signifier." Northampton MA: Media Education Foundation.
- Jonas, Michael. 2004. "On Racial Disparities, Biggest Gap is Between Talk and Accountability." *CommonWealth*. (Winter): 31-3.
- Jonathan, Skinner and J. Wennberg. 1998. "How Much is Enough? Efficiency and Medicare Spending in the Last Six Months of Life." Working Paper 6513, National Bureau of Economic Research.
- Johnson, Carolyn. 2004. "Medical Care: The Next Civil Right." *Boston Globe*. November 2. <http://www.boston.com>
- Johnson, Kirk and R. Abelson. 2005. "Model in Utah May be Future for Medicaid." *New York Times*: A1/8.
- Johnson, Marion and J.C. McCloskey (eds). 1993. *Economic Myths and Realities: Doing More With No More*. St. Louis MO: Mosby.
- Joseph, Miranda. 2002. *Against the Romance of Community*. Minneapolis: University of Minnesota Press.
- Kapur, Kanika and S. Marquis. 2003. "Health Insurance for Workers Who Lose Jobs: Implications for Various Schemes." *Health Affairs*. 22(3): 203-213.

- Katz, Steven, K. Cardiff *et al.* 2002. "Phantoms in the Snow: Canadians' Use of Health Care Services in the United States." *Health Affairs*. 21(3): 19-31.
- Kawachi, Ichiro and B. Kennedy. 2002. *The Health of Nations: Why Inequality is Harmful to Your Health*. New York: The New Press.
- Kawachi, Ichiro and L. Berkman (eds). 2003. *Neighborhoods and Health*. New York: Oxford University Press.
- Kawachi, Ichiro, N. Daniels and D. Robinson. 2005. "Health Disparities by Race and Class: Why Both Matter." *Health Affairs*. 24(2): 343-352.
- Keizer, Garret. 2005. "Life Everlasting: The Religious Right and the Right to Die." *Harpers Magazine*. 310(1857): 53-61.
- Kerber, Ross. 2004. "Medical Marketing: Device Makers Target Consumers with their Ads." *Boston Globe*. March 10. <http://www.boston.com>
- Kickbush, Ilona. 2004. "The End of Public Health As We Know It: Constructing Global Health in the 21st Century." A paper presented at the World Federation of Public Health Associations 10th International Congress on Public Health, Sustaining Public Health in a Changing World: Vision to Action, The Brighton Center, Brighton, UK April 19-22.
- Kilborn, Peter. 1998. "Black Americans Trailing Whites in Health, Studies Say," *New York Times* January 26: A16.
- Kingsbury, Paul. 2003. "Psychoanalysis, A Gay Spatial Science?" *Social and Cultural Geography*. 4(3): 347-367.
- Kirsch, Richard. 2003. "Will it Be Déjà Vu All Over Again? Renewing the Fight for Health Care for All, Tales, Hopes and Fears from a Battle Scarred Activist." <http://www.neaction.org/HealthCareDejaVuFinal.pdf>
- Klein, Joe. 2000. *The Natural: The Misunderstood Presidency of Bill Clinton*. New York: Random House.
- Klein, Karen. 2003. "Providing Care for Caregivers." <http://www.Newsday.com>. September 13.
- Kleinke, J.D. 2001. *Oxymorons: The Myth of a U.S. Health Care System*. San Francisco: Jossey Bass.
- _____. 2004. "Access Versus Excess: Value-Based Cost Sharing for Prescription Drugs." *Health Affairs*. 23 (1): 34-47
- Koehler, Christopher. 2001. "Science, 'Society' and Immunity." *Modern Drug Discovery*. 4(10): 59-60.

- Kohn, Linda T, J. M. Corrigan and M.S. Donaldson. 2000. *To Err is Human: Building a Safer Medical System*. Washington: National Academy Press.
- Kolata, Gina. 2005. "Rapid Rise and Fall of Body-Scanning Clinics." *New York Times*. January. <http://www.nyt.com>
- Kotlikoff, Laurence. 2004. "The Cheap Drug Trap." *The Boston Globe*. June 21: A11.
- Kraul, Chris. 2004. "Quest for Cheaper Drugs Can End in a Mexican Jail." *Los Angeles Times*. September 5. <http://www.latimes.com>
- Kretzmann, J.P. and J.L. McKnight. 1993. *Building Communities from the Inside Out: a Path Toward Finding and Mobilizing Community Assets*. Chicago: ACTA Publications.
- Kriss, Eric. 2004. "Budget Imbalance: The Rising Cost of Health Care Could Throw Off the Ecology of Government." *CommonWealth*. (Winter): 9-13.
- Kristeva, Julia. 2004. "Is There a Feminine Genius?" *Critical Inquiry*. 30(Spring): 493-504.
- Kristoff, Nicholas. 2005. "HealthCare? Ask Cuba.." *New York Times*. January 12. <http://www.nyt.com>
- Krugman, Paul. 2004. "Medical Class Warfare." *New York Times*. July 16. <http://www.nyt.com>
- Kurland, Judith and J. Zeder. 2001. "Coalition-Building: The Promise of Government." *American Journal of Community Psychology*. 29(2): 285-291.
- Kuttner, Robert. 2005. "Dollars to Doughnuts, Bush's Drug Benefits Is No Bargain." *The Boston Globe*. December 31: A11.
- Lacan, Jacques. 2002. *Ecrits*. New York: W.W. Norton.
- Lakoff, George. 1996. *Moral Politics: What Conservatives Know that Liberals Don't*. Chicago: University of Chicago Press.
- Leupin, Alexandre. 2004. *Lacan Today: Psychoanalysis, Science, Religion*. New York: Other Press.
- Levin, Kenneth. 2004. *Enterprise Hybrids and Alternative Growth Dynamics*. PhD Dissertation. Department of Economics. University of Massachusetts, Amherst.
- Leyshon, Andrew, R. Lee and C. Williams (eds.) 2003. *Alternative Economic Spaces*. London: SAGE.

- Lieberman, Trudy. 2003. "Bruised and Broken: U.S. Health System." *AARP Bulletin*. (March): 3.
- Light, Donald. 2002. "A Conservative Call for Universal Access to Health Care." *Penn Bioethics*. 9(4): 4-6.
- Lingis, Alphonso. 1994. *The Community of Those Who Have Nothing in Common*. Bloomington: Indiana University Press.
- Lohr, Steve. 2004. "Health Care Industry Seeks a Role Model." *New York Times*. October 31. <http://www.nyt.com>
- Lohr, Steve. 2004. "Is Kaiser the Future of American Health Care?" *New York Times*. October 31. <http://www.nyt.com>
- Lord, Robin. 2004. "Disabled Man Cut from State Insurance." *Cape Cod Times*. April 4: A1/A16.
- _____. 2004. "Seniors Snub Medicare Drug Card." *Cape Code Times*. June 22: B1/B2.
- Lundberg, George MD. 2000. *Severed Trust: Why American Medicine Hasn't Been Fixed*. New York: Basic Books.
- Lurie, Nicole, M. Jung and R. Lavizzo-Mourey. 2005. "Disparities and Quality Improvements: Federal Policy Levers." *Health Affairs*. 24(2): 354-364.
- Macherey, Pierre. 2004. "Out of Melancholia: Notes on Judith Butler's *The Psychic Life of Power: Theories in Subjection*." *Rethinking Marxism*. 16(1): 7-17.
- MacLeod, Greg. 1997. *From Mondragon to America: Experiments in Community Economic Development*. Sydney, Nova Scotia: University College of Cape Breton Press.
- Madra, Yahya. 2002. "Sublime Surplus of Communism." A paper presented at the Subjects of Economy Conference sponsored by *Rethinking Marxism*, University of Massachusetts, November 8.
- _____. 2006. "Questions of Communisms: Ethics, Ontology, Subjectivity." *Rethinking Marxism*. 18(2): 205-223.
- Marmor, Theodore. 1998. "Forecasting American Health Care: How We Got Here and Where We Might Be Going." In 1998. *Healthy Markets? The New Competition in Medical Care*. ed. Mark Peterson. 377-385. Durham NC: Duke University Press.
- Marx, K. 1978 "The German Ideology." In *The Marx-Engels Reader*. ed. Robert Tucker. New York: W.W. Norton.

- Massumi, Brian. 1996. "The Autonomy of Affect." In *Deleuze: A Critical Reader*. ed. Paul Patton. Oxford: Blackwell.
- Maxwell, James, P. Temin and S. Zaman. 2002. "The Benefits Divide: Health Care Purchasing in Retail Versus Other Sectors." *Health Affairs*. 21(5): 224-233.
- McCade, Dorthy. 2005. "Safe Minimum RN Staffing Standards: Quality Care & Protect Patient Safety." Presentation of the Massachusetts Nursing Association, First Baptist Church, Greenfield Massachusetts, April 27.
- McCourt, Matt. 2004. "Nurturing Space: Representations, Interventions, and Emergent Publics in Appalachian community Organizing." Paper presented at the 2004 Annual Meeting of the Association of American Geographers, Philadelphia, Pennsylvania, March 11.
- McKenzie, Nancy. 1994. *Beyond Crisis: Confronting Health Care in the United States*. New York: Meridian Books.
- McKnight, J. 1995. *The Careless Society: Community and its Counterfeits*. New York: Basic Books.
- McNamara, Beverly. 2001. *Fragile Lives: Death, Dying and Care*. Bukingham: Open University Press.
- Mei-hui Yang, Mayfair. 2000. "Putting Global Capitalism in its Place: Economic Hybridity, Bataille and Ritual Expenditure." *Current Anthropology*. 41(4): 477-495.
- Meyer, Jack and S. Silow-Carroll. 2003. "Building On the Job-Based Health Care System: What Would it Take?" *Health Affairs Web Exclusive*. (W3): 415-422.
- Miami Theory Collective. 1991. *Community at Loose Ends*. Minneapolis: University of Minnesota Press.
- Miligan, Christine. 2001. *Geographies of Care: Space, Place and the Voluntary Sector*. Burlington, VT: Ashgate Press.
- Miller, Jacques-Alain. 1994. "Extimite." In Mark Bracher (ed.) *Lacanian Theory of Discourse: Subject, Structure, and Society*. New York: New York University Press.
- _____. 2002. *The Tenderness of Terrorists and Other Letters Written by Jacques-Alain Miller to an Enlightened Public*. New York: Wooster Press.
- Miller, Matt. 2005. "Is Labor Out in Front on Health Care?" *New York Times*. February 13. <http://www.nyt.com>
- Mingione, E. 1991. *Fragmented Societies: A Sociology of Economic Life Beyond the Market Paradigm*. Oxford: B. Blackwell.

- Mishra, Raja. 2005. "Adult Diabetes Hitting Children: Obesity in Young Hikes Type 2 Cases." *Boston Globe*. June 12: A1/A26.
- Mitchell, Don. 1997. "State Restructuring and the Importance of 'Rights-Talk'." In *State Devolution in America*. eds. L. Statheli, J. Kodras and C. Flint. 118-138. Thousand Oaks CA: SAGE.
- _____. 2005. "The S.U.V. Model of Citizenship: Floating Bubbles, Buffer Zones, and the Rise of the 'Purely Atomic' Individual." *Political Geography* (24): 77-100.
- Mitchell, Juliet. 1983. "Introduction-I." In *Feminine Sexuality: Jacques Lacan and the école freudienne*. eds. J. Mitchell and J. Rose. New York and London: W.W. Norton and Co. 1-26.
- Moy, Ernest, E. Dayton and C. Clancy. 2005. "Complining the Evidence: The National Healthcare Disparities Report." *Health Affairs*. 24(2): 376-387.
- Mullan, Fitzugh. 2002. "Some Thoughts on the White-Follows-Green Law." *Health Affairs*. 21(1): 158-159.
- Mullen, Penelope. 1998. "Is it Necessary to Ration Health Care?" *Public Money & Management*. (January-March): 52-58.
- Murtaugh, Christopher *et al.* 2003. "Trends in Medicare Home Health Care: 1997-2001. The Balance Budget Act has been Successful in Reigning In the Use of Home Health Benefits and Shifting it Towards Skilled Services." *Health Affairs* 22(5): 146-156.
- N4A. 2004. "Home and Community-Based Services for Older Adults: Informal Caregiving." http://www.n4a.org/informal_caregiving_0207.pdf.
- Nakosteen, Robert. 1999. "The Pioneer Valley Region." *Mass Benchmarks*. 2(4): 10-15.
- Nancy, Jean-Luc. 1991. *The Inoperative Community*. Minneapolis MN: University of Minnesota Press.
- _____. 1992(a). "La Comparution/The Compearance: from the Existence of "Communism" to the Community of "Existence." *Political Theory*. 20(3): 371-397.
- Nancy, Jean-Luc and P. Lacoue-Labarthe. 1992(b). *The Title of the Letter: A Reading of Lacan*. Albany: State University of New York Press.
- Niesz, Helga. 2000. "National Family Caregiver Support Act." *OLR Research Report*. <http://www.cga.state.ct.us/2001/rpt/olr/htm2001-r-0750.htm>.
- Nichols, Len *et al.* 2004. "Are Market Forces Strong Enough to Deliver Efficient Health Care Systems?" *Health Affairs*. 23(2): 8-21.

- Neuman, Peter, M. Weinstein 2004. "Rational Rationing: There is a Way to Get the Most Health Care Bang for the Buck." *Commonwealth, Health Care Extra*. (Winter): 9-10.
- Norris, Andrew. 2005. "Stanley Cavell and the Claim to Community." *Theory and Event*. 8(1). http://muse.jhu.edu/journals/theory_and_event/
- Norris, Tyler. 2001. "America's Communities Movement: Investing in the Civic Landscape." *American Journal of Community Psychology*. 29(2): 301-308.
- Norton, Bruce. 2001. "Reading Marx for Class." In J.K. Gibson-Graham, S. Resnick and R. Wolff (eds). *Re/Presenting Class: Essays in Postmodern Marxism*. Durham, N.C.: Duke University Press. 23-55.
- Nuland, Sherwin. 2001. "Indoctrinology." *The New Republic*. <http://www.tnr.com/>
- Oakeshott, Robert. 2000. *Jobs and Fairness: the Logic and Experience of Employee Ownership*. Norwich UK: Michael Russell Publishing.
- Oberlander, Jon. 2003. "The Politics of Health Reform: Why Do Bad Things Happen to Good Plans?" *Health Affairs-Web Exclusive*. (W3): 391-404.
- O'Brien, Lawrence J. 1999. *Bad Medicine: How the American Medical Establishment Is Ruining Our Health care System*. Amherst NY: Prometheus Books.
- Offri, Danielle. 2003. *Singular Intimacies: Becoming a Doctor at Bellevue*. Boston: Beacon Press.
- _____. 2004. "Sometimes, Doctors Find Answers Far Off the Charts." *New York Times*. December 7.
- O'Leck, Joan. 2003. "Under the Radar." *Ford Foundation Report*. Summer.
- O'Neil Munding, Mary. 2002. "Through a Different Looking Glass: Advanced-Practice Nurses Don't Merely Substitute for Physicians; They provide a Sought after Model for Patient Care." *Health Affairs*. 21(1): 163-164.
- Özselçuk, Ceren. 2003. "Traversing Melancholic Attachments: Rethinking Working Class Politics in the Context of the Turkish Anti-privatization Movement." A talk given at the *Marxism and the World Stage Conference*, University of Massachusetts, Amherst, November 8.
- _____. 2006. "Mourning, Melancholy, and the Politics of Class Transformation." *Rethinking Marxism*. 18(2): 225-240.

- Özselçuk, Ceren and Y. Madra. 2005. "Marxism and Psychoanalysis: From Capitalist-all to Communist Non-all," *Psychoanalysis, Culture and Society*. 10(1): 79-98.
- Park, Edwin and Robert Greenstein. 2004. "Initial Data on Market Enrollment Fail to Dispel Concerns about Health Savings Accounts." *Center on Budget and Policy Priorities*, September 13th. <http://www.cbpp.org/9-13-04health2.htm>
- Patchett, Ann. 2003. "Caregiving: A Love Story." *Oprah*. (December):101-102
- Patton, Paul. 1996. *Deleuze: A Critical Reader*. Oxford: Blackwell.
- Pauly, Mark and M. Redisch. 1973. "The Not-for-Profit Hospital as Physicians Cooperative." *The American Economics Review*. 63(1): 87-99.
- Pavloskaya, M. 2002. "Other Transitions: Multiple Economies of Moscow Households in the 1990s." Unpublished paper, Department of Geography, Hunter College, New York, NY.
- Peabody, Francis. 1927. "The Care of the Patient." *Journal of the American Medical Association*. 88(12): 877-882.
- Pear, Robert. 2003. "New Study Finds 60 Million Uninsured During a Year." *New York Times*. May 13. <http://www.nyt.com>
- _____. 2004. "U.S. to Audit States' Medicaid Programs." *New York Times*. December 20. <http://www.nyt.com>
- _____. 2004. "Administration Looks to Curb Growth of Medicaid Spending." *New York Times*. December 20. <http://www.nyt.com>
- _____. 2005. "Health Costs Will Keep Rising, U.S. Says, Along With Government Share of Paying Them." *New York Times*: A8.
- Peck, Jamie. 2002. "Labor Zapped/Growth Restored? The Three Moments of Neoliberal Restructuring in the American Labor Market." *Journal of Economic Geography*. 2(1): 179-220.
- Pennsylvania Health Care Costs Containment Council. 2004. "Hospital Acquired Infections in Pennsylvania." *PHC4 Research Briefs*. 5(July): 1-4. <http://www.phc4.org/reports/researchbriefs/071205/default.htm>
- Peterson, Mark (ed). 1998. *Healthy Markets? The New Competition in Medical Care*. Durham NC: Duke University Press.
- Philo, C. 1992: Foucault's Geography. *Environment & Planning : D, Society and Space*. 10: 137-161.

- Philo, Chris and H. Parr. 2003. "Introducing Psychoanalytic Geographies." *Social and Cultural Geogrpaphy*. 4(3): 283-292.
- Popke, Jeffrey E. 2003. "Poststructuralist Ethics: Subjectivity, Responsibility and the Space of Community." *Progress in Human Geography*. 27(3): 298-316.
- Popper, Deborah E. and F. Popper. 1999. "The Buffalo Commons: Metaphor as Method." *Geographical Review*. 89(4): 491-510.
- Priselac, Thomas. 2003. "The Erosion of Health Insurance: The Unintended Consequences of Tiered Products by Health Plan." *Health Affairs*. 22(1): 158-161.
- Putnam, Robert. 1996. "The Strange Disappearance of Civic America." *The American Prospect*. (Winter): 734-759.
- Reinhardt, Uwe. 1997. "Reforming the Health Care System: The Universal Dilemma." In *The Social Medicine Reader*. eds. G. Henderson, N. King *et al*. Durham: Duke University Press: 446-457.
- _____. 2000. "International Perspective on Health Policy Reform." In *Social Security and Medicare*. eds. Sheila Burke, Eric Kingson and Uwe Reinhardt. 161-182. Washington DC: National Academy of Social Insurance..
- _____. 2002. "Analyzing Cause and Effect in the U.S. Physician Workforce." *Health Affairs*. 21(1): 165-166.
- _____. 2002. "Does the U.S. Tax-Financed Health Spending Really Incur Waste?" *Health Affairs*. 21(4): 99-100.
- _____. 2003. "Is There Hope for the Uninsured?" *Health Affairs Web Exclusive*. (W3): 376-390.
- _____. 2004. "Does the Aging of the Population Really Drive the Demand for Health Care?" *Health Affairs*. 22(6): 27-39.
- Resnick, Stephen and R. Wolff. 1987. *Knowledge and Class: a Marxian Critique of Political Economy*. Chicago: University of Chicago Press.
- _____. 2003. "Exploitation, Consumption and the Uniqueness of American Capitalism." *Historical Materialism*. 11(4): 209-227.
- Reuters. 2005. "Disparities in Care Kills 80,000 Blacks." <http://www.cnn.com/2005/HEALTH/03/10/race.disparities.reut/index.html>.
- Richmond, Alan. 2001. *HUD 242 Mortgage Banking & Financial Advisory Services for Rural, Community and Critical Access Hospitals*. Springfield PA: Innovative Capital.
http://www.ruralresource.org/documents/Alan_Richmond_Handout_1.pdf

- Robinson, Andrew. 2005. "The Political Theory of Constitutive Lack: A Critique." *Theory and Event*. 8(1). http://muse.jhu.edu/journals/theory_and_event/
- Rose, Jacqueline. 1996. "Introduction: Part Two." In Sachs, W. [1937]. *Black Hamlet*. Baltimore: John Hopkins University Press.
- Routledge, Paul. 2004. "Convergence of Commons: Progress Geographies of People's Global Action." *The Commoner*. 8 (Autumn/Winter): 1-19.
- Rowland, Christopher. 2004. "Drugmakers Try to Recast Lagging Image." *Boston Globe*, May 9: A1/14.
- Rowland, Christopher. 2005. "Shake-up Envisioned in Health Insurance, Higher Deductibles Seen Possible for Many." *Boston Globe*, November 7. <http://www.boston.com>
- Safri, Maliha. 2005. ".The Economics of Immigration: Household and Employment Dynamics in the US." Ph.D. Dissertation. Department of Economics. University of Massachusetts.
- Sagar, Alan. 2002. "Crafting an Affordable Medicare Prescription Drug Benefit: Lessons from the Veterans Administration Experience." Hearing on the Department of Veterans Affairs Prescription Drug Purchasing Program, Boston Massachusetts, July 22.
- Sagar, Alan. and D. Socolar, 2003. "Looming Meltdown in Massachusetts Demands Action." www.healthreformprogram.org
- Sagar, Alan and D. Socolar. 2004. "Ensuring a Supply of Affordable Drugs." *The Boston Globe*. June 21: A11.
- Sahney, Vinod. 2004. "Commentary on Plenty." In D. Berwick. *Escape Fire: Designs for the Future of Health Care*. San Francisco: Jossey-Bass. 269-271.
- St. Martin, Kevin. 2001. "Making Space for the Community Resource Management in Fisheries." *Annals of the Association of American Geographers* 91(1): 122-142.
- Samuelson, Robert. 2006. "The Fix-it Myth." *The Washington Post*. A: 25.
- Sandel, Michael. 2004. "Are we Still a Commonwealth? Markets, Morals and Civil Life." Commonwealth Humanities Lecture, National Heritage Museum, Lexington MA. June 10.
- Satcher, David G Fryer *et al.* . 2005. "What if We Were Equal? A Comparison of the Black-White Mortality Gap in 1960 and 2000." *Health Affairs*. 24(2): 459-464.

- Satel, Sally. 2004. "Don't Despair Over Disparities." *The Weekly Standard*. March 1. <http://www.weeklystandard.com/>
- Savage, Lydia. 2004. "Public Sector Unions Shaping Hospital Privatization: The Creation of Boston Medical Center." *Environment and Planning A*. (36): 547-568.
- Schrift, Alan. 1997. *The Logic of the Gift: Towards and Ethic of Generosity*. New York: Routledge.
- Schuller, Tom, S. Baron and J. Field. 2000. "Social Capital: A Review and Critique." In *Social Capital: Critical Perspectives*. eds. S. Baron, J. Field and T. Schuller 2-38. Oxford: Oxford University Press.
- Schwartz, Carolyn E. and M. Sprangers. 2000. *Adaptation to Changing Health: Response Shifts in Quality-of-life Research*. Washington: American Psychological Association.
- Scott, Nancy. 2005. "Life at the Top in America Isn't Just Better, It's Longer." *New York Times*. May 16. <http://www.nyt.com>
- Sen, Amartya. 1999. *Development as Freedom*. New York: Knopf.
- Shanin, T. 1988. "Expolary Economies: A Political Economy of Margins." *Journal of Historical Sociology* 1(1).
- . 1999. "Informal Economies and Expolary Structures in Contemporary Russia." In T. Shanin (ed). *Informal Economy: Russia and the World*. Moscow: Logos.
- Sharpe, Virginia A. and A.I. Faden. 1998. *Medical Harm: Historical, Conceptual, and Ethical Dimensions of Iatrogenic Illness*. Cambridge: Cambridge University Press.
- Shelton, Michael. 2000. *Talk of Power, Power of Talk: The 1994 Health Care Reform Debate and Beyond*. Westport Connecticut: Praeger.
- Shenkin, Henry. 1996. *Current Dilemmas in Medical-Care Rationing: A Pragmatic Approach*. Lanham, Maryland: University Press of America.
- Sibley, David. 2003. "Geography and Psychoanalysis: Tensions and Possibilities." *Social and Cultural Geography*. 4(3): 391-399.
- Skinner, Jonathan and J. Wennberg. 1998. "How Much is Enough? Efficiency and Medicare Spending in the Last Six Months of Life." Working paper 6513. <http://www.nber.org/papers/w6513>
- Smith, David. 2005. "Racial and Ethnic Health Disparities and the Unfinished Civil Rights Agenda." *Health Affairs*. 24(2): 317-324.

- Smith, Deborah. 2003. "Be Excellent to Each Other." *Oprah*. (December): 219.
- Smith, Erin. 2004. "New Hospital is First of its Kind to Benefit from Loan Program." *The Pueblo Chieftain*. August 10: 1 & 3.
- Smith, Jason. 2004. "I am Sure That You Are More Pessimistic Than I Am...' an Interview with Giorgio Agambem." *Rethinking Marxism*. 16(2): 119-124.
- Snyderman, Ralph, G. Sheldon and T. Bischoff. 2002. "Gauging Supply and Demand: The Challenging Quest to Predict the Future Physician Workforce." *Health Affairs*. 21(1): 167-168.
- Staeheli, Lynn. 2005. "Limits to Care?" A talk given at Critical Geography Mini-conference, Miami University, Oxford Ohio, October 28.
- Stavrakakis, Yannis. 1999. *Lacan and the Political*. London: Routledge.
- _____. 2003. "Reactivating the Democratic Revolution: The Politics of Transformation Beyond Reoccupation and Conformism." *Parallax*. 9(2): 56-71.
- Stone, Linda. "Medicare Reform Bill." *Elder Vision*. January/February 2004.
- Stuart, Bruce *et al.* 2003. "Employer-Sponsored Health Insurance and Prescription Drug Coverage for New Retirees: Dramatic Declines in Five Years." *Health Affairs Web Exclusive*. (W3): 334-341.
- Subramanian, Arvind. 2004. "Medicines, Patents, and TRIPS." *Finance and Development*. 41(1): 22-25.
- Szasz, Thomas. 2001. *Pharmacracy: Medicine and Politics in America*. Westport CT: Praeger.
- Taylor, Humphrey. 2002. "How and Why the Health Care System Will Collapse." *Health Affairs*. 21(6): 195-197.
- Thrift, Nigel. 2004. "Summoning Life." In *Envisioning Human Geographies*. P. Cloake, P. Crang and M. Goodwin (eds). London: Arnold. 81-103.
- Treaster, Joseph and Joel Brinkley. 2005. "Behind Those Medical Malpractice Rates." *New York Times*. February 22. <http://www.nyt.com>
- Trude, Sally *et al.* 2002. "Employer-Sponsored Health Insurance: Pressing Problems, Incremental Change." *Health Affairs*. 21(1): 66-75.
- Ubel, Peter A. 2000. *Pricing Life: Why it's Time for Health Care Rationing*. Cambridge MA: MIT press.

- U.S. Department of Commerce. 2004. *Pharmaceutical Price Controls in OECD Countries: Implications for U.S. Consumers, Pricing, Research and Development and Innovation*. Washington DC: International Trade Administration.
- Van Der Veen, Marjolein. 2001. "Beyond Slavery and Capitalism: Producing Class Difference in the Sex Industry." In *Representing Class: Essays in Postmodern Marxism*. eds. J.K. Gibson-Graham, S. Resnick and R. Wolff 121-142. Durham NC: Duke University Press.
- _____. 2002. "Rethinking Prostitution: Analyzing and Informal Sector Industry." Ph.D. Dissertation. Department of Economics. University of Massachusetts.
- Van Standen, Heinrich (translator). 1996. "In a Pure and Holy Way:" Personal and Professional Conduct in the Hippocratic Oath." *Journal of the History of Medicine and Allied Sciences*. 51: 406-408.
- Vladeck, Bruce. 2003. "Universal Health Insurance in the United States: Reflections on the Past, Present and Future." *American Journal of Public Health*. <http://www.healthpaonline.net/rekindling/Articles/Vladeck2.htm>
- Waldholz, Michael. 2002. "Call for Universal Health Care May Have a Chance This Time." *The Wall Street Journal*. October 15th. <http://www.healthpaonline.net>.
- Wallace, Paul. 2004. "The Health of Nations: A Survey of Health-Care Finance." *The Economist*. 372(8384): 1-19.
- Walsh, Stephen. 2004. "Health Savings Accounts and Patient Driven Care." <http://www.sfms.org/sfm/sfm604h.htm>
- Walshe, K. and S. Shortell. 2004. "When Things Go Wrong: How Health Care Organizations Deal With Major Failures." *Health Affairs*. 23(3): 103-111.
- Wallsten, Peter and M. Gold. 2004. "Medicare's Well-Being Suddenly a Key Issue." *Los Angeles Times*, Sunday, September 5. <http://www.latimes.com>
- Walters, James. 1997. *Choosing Who's to Live: Ethics and Aging*. Urbana: University of Illinois Press.
- Waring, Marilyn. 1984. *If Women Counted: A New Feminist Economics*. San Francisco: Harpers.
- Washington Post. 2004. "Medicare Costs to Rise 17.5%." *Hampshire Daily Gazette*. September 4: A1/A4.
- Wass, Hannelore, F.M. Berardo and R.A. Neimeyer (eds). 1988. *Dying: Facing the Facts*. New York: Hampshire Publishing Corporation.

- Welch, Charles. 2003. "Making Health Care Better, Cheaper, Safer." *Boston Globe*. May 12: 20.
- Weiner, Jonathan. 2002. "A Shortage of Physicians or a Surplus of Assumptions?" *Health Affairs*. 21(1): 160-162.
- Weiner, Ross. 2001. "Power Hitters Strike Out: New Perspectives On Baseball and Slavery." *Rethinking Marxism*. 15(1): 33-48.
- Wennberg, John. 1996. *The Dartmouth Atlas of Health Care in the United States*. Chicago: American Hospital Publishing.
- West, DM, D. Heith and C. Goodwin. 1996. "Harry and Louise Go to Washington: Political Advertising and Health Care Reform." *Journal of Health Politics, Policy and Law*. 21(1): 35-68.
- Williams, Collin. T. Aldridge and J. Tooke. 2003. "Alternative Exchange Spaces." In *Alternative Economic Spaces*. Ch. 7 London: SAGE. 151-167.
- Williams, Collin. 2003. "Developing Community Participation in Deprived Neighborhoods: A Critical Evaluation of the Third-Sector Approach." *Space and Polity*. 7(1): 65-73.
- Wilton, Robert. 2005. "Locating Physical Disability in Freudian and Lacanian Psychoanalysis: Problems and Prospects." *Social and Cultural Geographies*. 4(3):369-389.
- Wolff, Douglas. 2001. "Private Actions, Public Values: Towards a Social 'Balance Sheet.'" 17th Congress of the International Association of Gerontology, Vancouver, B.C. July 3.
- Wolff, Richard. 2003. "Take Step to Yale Paying City Fair Share." *New Haven Register*. June 26. <http://www.newhavenregister.com>
- Wolff, Thomas. 2001. "The Future of Community Coalition Building." *American Journal of Community Psychology*. 29(2): 265-270.
- Woolhandler, Steffie and D. Himmelstein. 2002. "Paying for National Health Insurance—And not Getting It." *Health Affairs*. 21(4): 88-104.
- _____. 2006. "Massachusetts Health Reform Bill: A False Promise of Universal Coverage." <http://www.commondreams.org>
- Wright, Elizabeth. 1999. *Speaking Desires Can be Dangerous: The Poetics of the Unconscious*. Cambridge MA: Polity Press.
- Žižek, Slavoj. 1991. *Looking Awry*. London: Verso.

- _____. 1994a. *For They Know Not What They Do: Enjoyment as a Political Factor*. London: Verso.
- _____. 1994b. "Is There a Cause of the Subject?" in *Supposing the Subject*. London: Verso. 84-100.
- _____. 2000a. "Melancholy and the Act." *Critical Inquiry*. 26 (summer): 657-681.
- _____. 2000b. *Tarrying With the Negative: Kant, Hegel and the Critique of Ideology*. Durham NC: Duke University Press.
- _____. 2000c. *The Fragile Absolute, or, Why is the Christian Legacy Worth Fighting For?* London: Verso.
- _____. 2001. "The Rhetorics of Power." *Diacritics*. 31(1): 91-104.
- _____. 2002. *Welcome to the Desert of the Real: Five Essays on September 11th and Related Dates*. London: Verso.
- _____. 2004a. "The Parallax View." *New Left Review*. (January/February): 121-134.
- _____. 2004b. "The Structure of Domination Today: A Lacanian View." *Journal of East European Thought*. (56): 383-403.
- _____. 2005. "Against Human Rights." *New Left Review*. (34):115-126.
- Zuger, Abigail. 2004. "Defining a Doctor, With a Tear, a Shrug and a Schedule." *The New York Times*. November 2.
- Zupan i , Alenka. 2000. *Ethics of the Real*. London: Verso.
- _____. 2005. "Enthusiasm, Anxiety and the Event." *Parallax*. 11(4): 31-45.