SOCIAL IDENTITY, AGENCY AND THE POLITICS OF ADHERENCE TO ANTIRETROVIRAL THERAPY IN HIV/AIDS CARE

by

SUZE GILLIAN BERKHOUT

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ABSTRACT

Within Vancouver’s Downtown Eastside community, gendered disparities exist with respect to uptake and continuity of antiretroviral therapy; limited access and adherence to therapy is commonly reported in the medical literature concerning women in the community. These findings are particularly hard to reconcile, as HIV treatment exists amidst a range of neighbourhood health and social support services that are ostensibly accessible to all through a universal health care system.

In this dissertation, I examine conventional approaches to facilitating treatment uptake and adherence along with dominant narratives employed to explain treatment challenges faced by women in Downtown Eastside Vancouver. Bringing together discourse analysis, qualitative interviewing, and participant observation with HIV-positive women and their health care providers I propose an alternate lens with which to examine gender disparities in HIV care. I argue that discourses of adherence to antiretroviral therapy are suffused with cultural imagery and tropes associated with women at high risk of HIV infection: images of sex work, drug use, homelessness, and mental illness. Additionally, an individualist, rationalist bias exists within much of the North American literature regarding women’s access and adherence to care; the literature finds points of convergence with larger normative frameworks of liberalism within medical practices.

Contrary to a conventional emphasis on psychosocial “barriers” to care, I focus on social interests, institutional authorities, relations of power, and strategies of social control. These are exerted on, resisted, and internalized by women attempting to negotiate care. I also suggest how a normative liberal framework underpinning HIV research and care may have the inadvertent consequence of further entrenching images of HIV positive women as deviant, dangerous, and/or irrational. My reframing issues of access and adherence as matters of negotiation and negative
agency leads me to discuss the ways in which liberal conceptions of autonomous agency are employed within discourses of HIV/AIDS care, structuring health care decision making and possible courses of action. The arguments I offer endorse a constitutively relational account of the self and autonomy. A relational account can, I argue, provide insight and guidance concerning adherence to antiretroviral therapy.
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LIST OF ABBREVIATIONS

AMA Against Medical Advice
ARV Antiretroviral
ART Antiretroviral Therapy
CHC Community Health Centre
DOT Directly Observed Therapy
HAART Highly Active Antiretroviral Therapy
FASD Fetal Alcohol Spectrum Disorder
FSW Female Sex Worker
IDU Injection Drug User
IVDU Intravenous Drug User
MAR Medication Administration Record
MAT Maximally Assisted Therapy
MMT Methadone Maintenance Therapy
MSM Men Who Have Sex With Men
NNRTI Non-Nucleoside Reverse Transcriptase Inhibitor
RHA Regional Health Authority
SRO Single Room Occupancy
VCH Vancouver Coastal Health
V/RHB Vancouver/Richmond Health Board
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For my parents, who have made this possible...
INTRODUCTION
“1.4-BILLION HAS BEEN SPENT, BUT TO WHAT END?”

The headline bellows “The Money Pit,” and a map of the area sits atop an allopathic and militaristic depiction of the neighbourhood as “ground zero.” A column of statistical figures classifies its residents as “poor and uneducated.” A subheading abruptly states “One Room For the Homeless: $326,484.” On February 14, 2009, The Globe and Mail launched its report on the public and private funds that have been spent in an attempt to improve Vancouver’s Downtown Eastside neighbourhood, since the signing of the Vancouver Agreement in 2000. The Vancouver Agreement saw three levels of government make a commitment to address the pressing needs of the inner city community, in light of a rash of drug overdose deaths in the 1990’s and sustained hepatitis C and HIV/AIDS epidemics.1 This is a community that is notorious for its open drug market, its prevalence of HIV/AIDS, and the location as North America’s first public injecting facility. The newspaper’s verdict:

The neighbourhood remains a vortex that sucks in junkies, the mentally ill and other desperate souls from across the country…More than $1.4-billion later, the Downtown Eastside is hardly better off. (The Globe and Mail, 2009)

The investigation concludes that what is possibly most problematic about all the funds funneled into the neighbourhood through the agreement is that nobody has been keeping track of the spending. One proposed solution: a Downtown Eastside “Czar” who would oversee the rehabilitation of the community and ensure accountability.2

In many ways, the Globe and Mail series is an exemplar of one of the dominant lenses through which Vancouver’s Downtown Eastside is viewed by popular press and wider society. The lead article’s artistic photography and personal narratives of a half-dozen neighbourhood residents belie the underlying populist rhetoric that makes it seem as though the money has been going straight to the pockets of community members, rather than funding policing positions, health care staff, non-profit organizations and the contracting businesses charged with renovating
the crumbling single room occupancy (SRO) hotels in the neighbourhood. Individuals who staff these positions overwhelmingly live in less maligned neighbourhoods in the metropolitan Vancouver area, their status as beneficiaries of public and private spending not deemed particularly notable.

The article questions where the “flood of spending” has gone to, depicting the targets as a “few squalid blocks” and a couple of thousand individuals with the most complex issues, but it inevitably fails to mention years of budgetary cutbacks and loss of housing and social services prior to the Agreement, in this community as well as many others. And indeed, the most vulnerable individuals are likely to move into downtown eastside Vancouver as affordable housing and social services are reduced elsewhere across the province. In addition, the focus on the drug market, problems of addiction, and the newspaper’s determination that the costly drug court has failed as an experiment serves to conflate the neighbourhood with the practices of injection drug use, setting the inner city in opposition to other communities in which drug use occurs. These other communities remain relatively unrepresented in public discourse, as drug use here exists predominantly within the privacy of peoples’ homes.

Commonly, the so-called general public fails likewise to see itself as the beneficiaries of social policy and social services. Roads, water treatment, hospitals, and schools are examples of the invisible infrastructure enabling people to move easily from place to place and carry out their personal projects as though they were making their way on sheer grit, determination, and occasional good fortune. In contrast, those who receive social assistance and disability services, like those who partake in programs that divert individuals from receiving jail time for minor drug-related offenses, are seen as living off the public purse and receiving unfair advantages. These conceptualizations both reflect and generate the type of language employed within the series of articles: that of “junkies,” the mentally ill, the homeless, and the image of the neighbourhood as “a Third World country stuck in the middle of downtown Vancouver.”
Persuasive rhetoric and images of the community and its residents function to sever it from a fictive ideal populace, supposedly constituted by rational, coherent, drug-free individuals. The notion of “Third World” conditions calls to mind images of global Others; the status of “Other” is most strongly applied to Aboriginal people in the community. Vancouver has been built up on traditional Coast Salish territory; the Coast Salish who survived the influenza, smallpox, and tuberculosis epidemics during first European contact were predominantly relocated to the reserve spaces designated by the Indian Act. Today, the Downtown Eastside is home to Aboriginal residents from across Canada and the United States, who disproportionately face social and economic disadvantage (Robertson and Culhane 2005, 16; Kelm 1998, xv). Referring to the heterogeneous grouping as a population and employing terms such as “overrepresentation” silently summons the need for a pastoral/colonial power for the community.7 The suggestion to appoint a “Czar” can be read as mimetic of Canada’s internal colonial relations; a reminder of earlier assimilative goals and the “white man’s burden.”8

My interest in the lens offered by the newspaper’s series is its effectiveness as an analytic prompt; it gestures toward a number of the underlying assumptions and imagistic figurations related to HIV infection and treatment in this inner city community. One set of concerns that I bring to this work is the influence of pernicious imagery and prejudicial figurations on medical practices, policy, and research; imagery can authorize discriminations and structure moral choices and epistemic projects (Meyers 1994, 53). Culturally entrenched figurations of socially excluded groups (“the junkie,” “the criminal,” and “the mad”), like those employed by the Globe and Mail series, have a way of becoming fundamental organizing principles (54) that extend well beyond the individual imagination to structures and institutions that shape how people are able to interact with one another and move about in the world. Just as the neighbourhood is offered up as a microcosm of pathology, transgression, and licentiousness in comparison to the rest of
society, the caricatures who populate the area are held against the image of a “general” public constituted by generic, universal, rational, autonomous agents.

STATS AND FIGURES: CONSTRUCTING HIV/AIDS IN THE COMMUNITY

The HIV epidemic has been described as running through society’s fissures, exposing underlying systems of social and economic privilege and advantage. In Canada, as elsewhere, there are disparities in the rates of HIV infection between women and men; infections among women have continued to rise across the country, from 11.3% of infections where sex was reported in the time between 1985 and 1996, to approximately 24% of new infections in 2002 and 27% of new adult infections in 2006 (PHAC 2007). Disparities in both infection rates and treatment uptake are substantial for Aboriginal persons. In 2006, Aboriginal women amongst accounted for nearly half (approximately 48%) of new infections amongst Aboriginal persons; in comparison, women account for 20% of new infections amongst all those identified as non-Aboriginal (PHAC 2007).

Care should be taken to ensure that one does not read this as suggesting that Aboriginal ethnicity is tantamount to a “risk factor.” Canada’s colonial history and racialized structuring of disadvantage are manifest in health statistics and outcomes; taking this to indicate something other than structural racism is likewise part of a colonial imaginary. The disparities are compelling: in 2006, targeted surveillance data in British Columbia demonstrated that Aboriginal women accounted for approximately 36% of new HIV infections amongst women; approximately 9% of the new infections amongst men were Aboriginal men (BC CDC, 2006). The infection rate amongst Aboriginal persons is estimated by the Public Health Agency of Canada to be 2.8 times higher than amongst non-Aboriginal persons. Aboriginal persons are less likely to receive treatment and amongst those accessing highly active antiretroviral therapy (HAART) they face higher rates of mortality and sub-optimal therapy (Wood et al., 2003; Miller et al., 2006; Lima et al., 2006). Epidemiological investigations of HIV infection rates in
Vancouver typically connect racialized and gendered disparities in HIV infection rates and treatment uptake to differences in frequency of injection drug use, participation in survival sex work, poor mental health, and history of sexual abuse, among other psycho-social determinants of risk.

In 1997, the Vancouver-Richmond Health Board declared a public emergency in response to reports that HIV infection among Downtown Eastside residents exceeded those in any other part of the “developed” world, with higher prevalence among female injection drug users (IDU) than males.\textsuperscript{12} Vancouver’s Downtown Eastside is frequently cited as one of Canada’s poorest postal codes;\textsuperscript{13} poverty, crowded living conditions, drug use, and dependency on survival sex work are visible parts of daily life in an area that has been likened by the press to something out of Dante’s inferno.\textsuperscript{14} Housing for many residents consists of single room-occupancy (SRO) hotels in the neighbourhood—although government assistance levels for housing and rent rates in the SRO system are at parity, the accommodations within the residential hotels are substandard. Residents contend with crumbling buildings, infestations, drug dealing, and illegal subletting. The Downtown Eastside is often described by its residents as a “petri dish”—it is a decidedly studied space where research honoraria contribute significantly to individuals’ incomes.\textsuperscript{15} Participants often take part in more than one cohort study, which limits the number of unique individuals represented by the data generated on the neighbourhood.

A substantial body of epidemiological literature examining access and adherence to treatment in Vancouver’s Downtown Eastside is derived from four large prospective cohort studies run out of the BC Centre for Excellence in HIV/AIDS [“the Centre”].\textsuperscript{16} Individuals’ responses to survey questions regarding all manner of behavioural and medical events are linked electronically to the Centre’s Drug Treatment Program, the centrally administered province-wide program through which all individuals accessing antiretroviral therapy (ART) receive their medications free of charge. Survey questions are similarly coded, such that discussions of risk
behaviours are comparable across cohorts.\textsuperscript{17} Data from one cross-sectional analysis have been referenced in subsequent analyses of the same cohort as a way of ‘generalizing’ findings.\textsuperscript{18} Contradictions do exist regarding the significance of socio-demographic variables and risk behaviours on treatment uptake and adherence, but conflicting studies nevertheless drive home similar concluding messages concerning drug users’ needs for structure and surveillance and the community’s need for more research.\textsuperscript{19}

Neighbourhood level data are also of interest to researchers as proxy measures of risk. For instance, one peer-reviewed article specifically examines the DTES neighbourhood as an independent risk factor for HIV infection among injection drug users. The authors write, “it is possible that the DTES may act not only as an epicenter of drug distribution, but also potentially for the spread of infectious disease,” as well as, “place of residence may act as a proxy for risk behaviours that are often not captured at an individual level in conventional epidemiological studies” (Maas et al., 2007). In this paper, individual behavioural data from one of the BC Centre for Excellence cohorts (the Vancouver Injection Drug User Survey, VIDUS) is pulled together to investigate an ecological hypothesis, leading to the claim that there is a “need for neighbourhood-specific public health initiatives to mitigate the observed higher risk.”

For as valuable as a wider community and public health emphasis might be, epidemiological studies of the Downtown Eastside link together to discursively constitute the “DTES,” as it is often demarcated in journal articles, newspapers and medical charts.\textsuperscript{20} As depicted in the Globe and Mail series, the four letters have become a handle for “marginalized urban population,” a descriptor often used in reference to both the IDU and the wider Downtown Eastside community.\textsuperscript{21} The visibility of the drug market and the prevalence of HIV are sufficient to allow the whole of the community to be represented by the practice of injection and the myriad data related to it. Similarly, women who take part in the IDU studies are also identified through a binary of sex worker/not sex worker\textsuperscript{22} and tagged as “FSWs,” (female sex
workers) reinforcing an assumption that people can be easily grouped into demographic
categories and that women in the community are sex workers, or at least willing to sell sex for the right price.\textsuperscript{23}

\textbf{WOMEN, HIV/AIDS, AND BARRIERS TO CARE}

Gender violence, socio-economic inequality, and violations of women’s human rights are reiterated drivers of women’s vulnerability to HIV and lack of treatment access in Vancouver’s inner city. Women exposed to HIV in the Downtown Eastside are described as being young, involved in so-called “high risk lifestyles” including the use of injection drugs and participation in survival sex work; they commonly face sexual, psychological, and physical forms of violence. Women who receive HIV medications are less likely to remain on treatment over longitudinal follow-up (Miller et al. 2002; Spittal et al. 2002). Treatment barriers are described in both research and practice as resulting from limited information, minimal self-efficacy, diminished cognitive function (either due to addiction, the effects of fetal alcohol spectrum disorder (FASD), mental illness or the neuropsychiatric complications of HIV infection itself), and street-entrenched lifestyles (Shannon et al. 2005b; Kerr et al. 2004; Alfonso et al. 2006).\textsuperscript{24} Barriers to adherence to HIV care are described as variable amongst different groups of individuals, but typically boil down to medication factors (e.g. side effects, complexity of regimen), externalities that complicate follow through (e.g. drug use), patient’s mood (e.g. depressed), outcome expectancies and level of support (Alfonso and Toy 2007; Kerr et al. 2004; Chesney et al., 2000; Lima et al., 2007).

Statistically though, women in the community do utilize high rates of primary, emergency, community nursing care, and various harm reduction services (Shannon et al. 2005, Kerr et al., 2004, Solomon et al., 1998). Within community clinics and supportive housing, there are a number of advocates, social workers, and community support workers who are able to assist individual in navigating the ‘system,’ be it healthcare, income assistance, disability
benefits, or otherwise. Education and health promotion materials regarding HIV risk are frequently seen posted in a number of clinical and social settings; information sessions relating to HIV and HCV in particular are offered at programs such as the Carnegie Centre, WISH, Vancouver Native Health Society, and so on. Similarly, numerous programs have been developed within the Health Authority to try and address issues around continuity of care and the transition between community clinics and hospital.

That said, HIV incidence continues to remain high, while treatment continuity consistently low amongst women in the community. This discord is particularly challenging to reconcile given the plethora of health and social support services that appear to be widely available, not the least because of a universal health care system. Likewise, there have been vast improvements in the simplicity and tolerability of HIV treatment. In light of these factors, we would expect women in the community to be able to do well on therapy – and yet, good clinical outcomes remain elusive.

I spent a great deal of time with a small number of women in the community, each of whom used a number of different illicit drugs; some were unstably housed and some were on and off their HIV medications through the study period. For all of the benefits of HIV treatment, it was extremely difficult for these women to achieve the sorts of health outcomes promised by contemporary medicine. Part of what motivates this project is a desire to understand the sorts of challenges that exist where there ought to have been straightforward treatment success. In answering this question, this project is critical of research and health policy that suggests that women in the downtown eastside community, especially Aboriginal women, have worse health outcomes and trouble adhering to antiretroviral therapy because they, as drug users, are either irrational, irresponsible, or incompetent.

In order to get at the underlying dynamics of the statistics, I examine the health care experiences of a small group of HIV-positive women, living in the inner city of Vancouver,
Canada. The significance of the site is three-fold. First, the inner city is a location where access
to treatment is not merely an issue of health insurance coverage and medication costs. In other
settings, the task of disentangling the economics of health from other barriers to care for the
urban poor can be Sisyphean in nature. Here, individual medical care is available through a
number of publicly funded clinics, run by the Regional Health Authority, or contracted by the
Authority to particular agencies or societies. That said, while barriers are not strictly a matter of
finances, economic disparities are deeply connected to health within this setting.

Second, as the Globe and Mail report focuses so raptly on, Vancouver is home to what is
often called the “world’s largest open drug market,” symbolized by the intersection of Main and
Hastings. Practices of drug injection have driven the HIV epidemic in the community and
popular ideas about drug use profoundly shape the experiences of individuals who live there.
Finally, as I have begun to detail, the Downtown Eastside is a location where we see reflections
of Canada’s colonial history, devastating effects of intergenerational disruption from residential
schooling as well as assimilation policies, the province’s history of *terra nullius*, and a wider
lack of recognition of racism in Canada.25

These considerations bring forward a number of major thematic issues within the
research. First, I attempt to address effects of intersecting stereotypes, images, and figurations
attached to multiple social identities of the individuals who took part in the project and
graciously allowed me to use their life stories in an effort to understand complexities and
tensions in adhering to antiretroviral therapy. Second, it was the application of these images that
led me to question uses of classificatory schemas in clinical practice and medical research—IDU,
FSW, MSM,26 and so on. Presumptions of objectivity and neutrality in scientific methods
strengthen notions that such categories are merely descriptive and not constitutive of reality.
Finally, I focus to a great extent on drug use and images and figurations that women identified as
being ascribed to them because of their classification as “addicts.” Pernicious images and
figurations of excluded social groups have a way of reinforcing one another, as social identities have multiple and dynamically intersecting aspects. Categorization makes it seem as though there are clean groupings to which one belongs; when the images of one grouping overlap with those of another, the clean borders of the category make it difficult to see how they are interrelated. But of course they are; categorization may serve to perpetuate systemic forms of disadvantage, while making it increasingly difficult to identify its causes.

Although I do not give the same attention to theorizing the way in which categorizing women as Aboriginal plays in their experiences within the health care system, my comments above should make it clear that my emphasis on drug use by no means suggests ethnicity is insignificant, or even a separate issue. A different study might begin from this social identity and move outward from it, in a manner similar to the methods I employ here. My own focus on identities associated with drug use is not to say that this is primary or most important—it is merely a starting point.

**SOME CRITICAL CHALLENGES**

Epidemiological data relating to HIV/AIDS and its treatment in the Downtown Eastside, along with media depictions of the community, constitute what might be termed a dominant narrative of HIV care for women in the community. Mental illness, exposure to violence, and uncontrolled addiction are reiterated as the ubiquitous characteristics of the community, as well as the drivers of non-engagement with health services and non-adherence to ART. The “scale up” of HIV treatment—through a proposed set of weakly paternalistic interventions backed by clinical researchers and health policy makers—is buttressed by an emphasis on cognitive challenges for continuity of ART. Hovering below the surface of dominant narratives of access and adherence to HIV care, are underlying notions of threats to public health, particularly as increasing attention is being drawn to the role of HAART as a means of preventing further transmission of HIV as an effect of reduced community viral load. Given depictions of HIV
positive individuals in the eastside, treatment programs in the community emphasize a need for daily witnessed ingestions and a linking of methadone maintenance therapy with ART, along with increased outreach of medical services into typically non-clinical spaces within the community.

Conventional accounts of access to HIV care in the Downtown Eastside tempt their readers to absorb ideas that co-morbid problems of substance use and HIV infection in the area are a result of limited health programming, rampant untreated mental illness, and individual level “chaos” and deviance, tied to perpetual involvement in an open drug market. Although I provide a more in-depth analysis of medical literature regarding access and adherence to ART in the following chapter, my initial sketch of dominant conceptualizations of the access/adherence problem will suffice to begin to tease apart the language and implications of this discourse.

In contrast to conventional understandings of the disparities in treatment uptake as being problems of lifestyle choices, personal motivation, and pragmatic considerations related to addiction, mental health, and victimization, I propose to add historical and political depth to the statistical discrepancies in rates of infections and enrollment in treatment for women in Vancouver’s inner city. My own contribution to the plethora of research on HIV/AIDS in the Downtown Eastside is to offer multiple vantage points and competing narratives of HIV care in order to afford glimpses of ways in which engagement in medical institutions and adherence to ART is also an issue deeply connected to axes of social power and privilege.

Importantly, I argue that conventional narratives of who requires greater medical interventions and structuring of their health care services and why these individuals are unable to otherwise adhere to medical advice are informed by an instituted social imaginary of rational autonomous agency, widely shared within the early 21st century affluent western world. This is a loosely integrated system of images, metaphors, tacit assumptions, and ways of engaging with the world that holds instrumental reason, rational action, and autonomous agency as central
features of human beings (Code 2006, 30-34). The social imaginary finds favour with a
normative framework given by liberal humanism. This framework structures how adherence to
antiretroviral therapy and following of medical advice are conceived of within HIV/AIDS
research and clinical care, through its connection to a rational actor model and individualist view
of the self.

RATIONAL ACTORS AND AUTONOMOUS AGENTS IN MEDICAL DISCOURSE

Mythologized conceptualizations of rational autonomous agency, given from a tradition
of liberal thought, exist in a matrix of practices, policies, procedures, physical, and rhetorical
spaces of HIV/AIDS research and care. Imagistically opposing this idealized rational actor are
populist figurations and media representations of the Downtown Eastside neighbourhood and its
residents. These images are also embedded to varying degrees within the medical and research
practices that are geared toward identifying, studying, and treating HIV/AIDS in the community.
This project investigates the instantiations of the liberal ideals of rationality, universality, and
objectivity within biomedical discourses and draws connections between these discourses and
the naturalization of patterns of HIV-related pathology associated with non-adherence to ART.

“Compliance” has largely fallen out of fashion as it has been argued to denote submission
and passivity on the part of patients, suggest disobedience and recalcitrance, and frame issues
associated with following medical advice from the perspective of health care providers (Conrad
1985). “Adherence” is preferred, describing the extent to which patients’ actions accurately
follow recommendations given to them from health providers. If we look at what constitutes
non-adherence to ART, the definition of adherence is remarkably similar to that of compliance.
Within both clinical practice and biomedical research, non-adherence describes patients who: fail
to fill prescriptions, take medications improperly, forget medications, self-adjust their dose, take
only part of a regimen, or terminate a regimen (Alfonso and Toy, 2007). What unifies each of
these as acts of non-adherence in HIV/AIDS literature is that a patient’s behaviour fails to
correspond with their health provider’s recommendations, resulting in a failure to have each component of combination therapy enter the body each time it was prescribed to be ingested.27

Even within the current era of shared decision-making and patient-centered care in medicine, it seems that following medical advice just is the rational thing to do. And for all intents and purposes, there is a good fit between a rational actor model of action and the literature concerning adherence to ART. Although there are differences between clinical versus research environments where conceptualizations of adherence are operationalized (within clinical settings, a wider set of issues is contended with than only medication ingestion), these wider forms of adherence to medical advice are also conceived of through an instrumentalist style of rational actor models.

As a current condition of HIV treatment for many patients, witnessed ingestion of medications is common and directly observed therapy programs are slated to be part of treatment scale-up.28 Given that drug use, mental illness and other factors typically associated with failures of autonomy are depicted as ubiquitous, medical interventions that focus on providing a paternalistic corrective to limited autonomy are unsurprising. But we can also problematize the grounds upon which these clinical injunctions rest, as I intend to do. Relationships between populist images, a social imaginary of autonomous agency, and methods of generating adherence data according to risk classifications are fodder for my critique. The manner by which these disparate issues come together within the medical system may generate the very conditions that are taken as evidence for the necessity of paternalistic interventions.

For instance, if we appreciate how a patient’s sense of surveillance and lack of control over their experience with medical care is a problem for long-term adherence and we see that individuals who have been ascribed social identities that conjure up notions of irresponsibility, incompetence, and irrationality are more likely to be subject to surveillance and control measures, we can make a connection between their lack of engagement in long-term adherence
and conditions under which treatment is offered to them as a “choice.” But making such a connection requires us to grapple with the constructedness of social identity categories and normative frameworks underlying the reasonableness of “choices” that people are given in the health care system. This is not a straightforward task; it is further troubled by the way in which a refusal to engage in treatment or a withdrawal from health care programs serves to reinforce the cogency of the original pejorative imagery. The issues here are deep philosophical ones: the “self,” identity, agency, and autonomy. They will not be easily picked out from survey questionnaires, standardized tests, or validated instruments. They require a different approach to conceptualizing, studying and interpreting adherence to ART, which I offer here.

**THE MEDICAL “SELF”**

The ethos of contemporary society in the affluent west is arguably a “regime of the self” (Rose 1996, 1). Methodological individualism informs current political and moral conceptual schemas within North America (and western Europe); the autonomous self is the basis for claims of individual rights as well as both positive and negative liberties; self-identities and the kinds of person we take ourselves to be shape how we conceive of our range of possible actions. In many ways, this project is an attempt to understand some of the roles that medical institutions have in constructing and attributing identities and how those constructions and attributions have regulative functions. This sort of concern is familiar territory to medical sociologists and anthropologists. I confess that little of what I say here will push the boundaries of critical and scholarly work in these fields. I recognize that I am unable to give an elaborate discussion of the intellectual history of understandings of the self in medical sociology. What I do hope to accomplish, though, is an interrogation of conventional thinking in liberal moral and political philosophy, as well as in medical discourses surrounding HIV/AIDS care, by bringing to bear upon these a number of well-developed analyses of the interrelations of self and medicine from poststructuralist and postmodernist thought in the social sciences and humanities. In many ways
I am interloping within what would otherwise be the domain of social theory, but I do so in order to speak to various regulative and normative functions of biomedicine and draw connections with philosophical frameworks that operate within its practices.

Keeping this overall aim of the research in mind, I hope it will be somewhat less offensive to scholars in the social sciences that I employ terms such as “the self,” when their own discursive practices would utilize concepts such as “subjectivity” or “subject position.” Concepts such as the latter carry with them linguistic, historical, and political connotations. While cognizant of them, I often leave these connotations unstated or under-theorized, though in a somewhat strategic fashion. Likewise I hope that readers from within the social sciences are able to recognize that my use of a concept such as “the self” is a pragmatic rhetorical choice so as to enable and enhance a dialogue within contemporary Anglo-American philosophy, which is all too often oblivious to the various issues and concerns of critical thought in the social sciences. The same could be said for my use of “social identity.” I have tried to apply care in my discussion of “identities,” making explicit for instance, when I refer to a set of ascribed characteristics based on actual or presumed group membership. I try to avoid giving the impression that I take the notion of “identity” to be a form of self-authored definition that others recognize and reflect back to an individual. As much as “identity” in this respect has an important theoretical role to play in my analysis, I myself do not employ this understanding of identity as though it were straightforward and unproblematic.

Central to much of my discussion concerning medicine and the “self” are some of the works of Michel Foucault, and in particular, contemporary Foucauldian scholars who apply and extend Foucault’s concepts of governmentality, biopolitics, disciplinary regimes, and technologies of the self to issues of identity and the self in modern medicine. While I recognize that much of my use of this work is under-theorized, I hope that scholars will be charitable in their reading, given the purposes of the project. As Robin Bunton and Alan Petersen write in
their introduction to *Foucault: Health and Medicine*, Foucault’s own approach crisscrossed disciplinary boundaries in order to make links between previously distinct areas (Bunton and Petersen 1997, 1). As I say though, I am not offering a Foucauldian analysis of adherence to ART or of the normative elements of current biomedical practices—I am attempting to critique dominant narratives and conventional frameworks in these areas from my position within Anglo-American analytic philosophy; where Foucault’s scholarship is able to contribute to my critique, I draw upon it.

This is particularly significant with respect to the place of medicine in fabrications of identities and self-understandings. David Armstrong describes this aspect of Foucault’s work as embedded in the subtext of *Birth of the Clinic* (trans. 1973), clarified in *Discipline and Punish* (trans. 1977), and articulated more explicitly in *History of Sexuality* (trans. 1978) (Armstrong 1997, 19-27). The important lessons I take from this intellectual trajectory are: historical and cultural location of medical practices make possible certain ways of seeing, knowing, and being; clinical practices are integral and constituting aspects of individual experience; biomedicine is one of a number of normalizing institutions; and biomedical authority, granted on the basis of having offered explanations of and solutions to various “problems,” is disguised to a great degree by its voluntary uptake on the part of individuals (Armstrong 1997; Foucault 1973, 1978; Petrina 2008; Turner 1997). With regard to this last consideration, *Technologies of the Self* (1988) also offers an important theoretical resource that I rely on in my analysis of feminist scholarship of autonomous agency in bioethics.

In addition, I draw upon a number of other theoretical/conceptual resources, most notably feminist works in philosophy of science, epistemology, and especially ethics. Where it is unclear or open for debate as to whether the ontological and epistemological commitments of these diverse bodies of literature might conflict with one another, I have tried to make a case for their use together. One certainly ought not to go about cherry-picking philosophical views without an
eye to their theoretical commitments, but I do not suppose my interdisciplinary methodologies and analysis to be overly susceptible to this complaint.

ABOUT THE DISSERTATION

The HIV/AIDS epidemic and the gendered and racialized disparities in long term treatment utilization and outcomes are part of a crisis, but this crisis was not discovered by any one news agency or research body, to be fixed in a one-night forum or through the installment experts who will oversee the supposedly disordered community. Too often, media depictions (along with policy suggestions based on these) only begin to scrape the surface of a complicated web of issues that surround substance use and HIV care in the inner city. They have a tendency to reinforce dominant narratives, imaginaries, and explanations of treatment access that do little more than pathologize particular individuals, while failing to examine underlying structural and interpersonal dynamics influencing health care. Disparities in morbidity and mortality rates for HIV positive people in the Downtown Eastside, in the current day, cannot be seen as isolated from effects of social policy in the preceding decades, nor from gender-based oppression, nor from histories of Euro-Canadian domination.

Particular conceptions of disparities in treatment outcomes amongst women in the community have a tendency to mask certain politics of negotiating health within institutional settings of health services. The qualitative research I have carried out will show how it is within rhetorical and physical spaces of such negotiations that contours of agency are drawn and re-drawn. By applying tools of feminist philosophical analysis to wider social and historical conditions of women’s engagement with HIV care and the allopathic medical system, I intend to re-set the sights of adherence discourse on the ways in which social interests, institutional authorities, relations of power, and strategies of social control are exerted on, resisted, and internalized by women living in the inner city, as they attempt to navigate the warren of locations in which HIV care occurs. The stakes here are not simply an alternate conceptualization of
gendered disparities in HIV treatment and adherence to therapy—if my analysis is on target, my refutation of idealizations of rational agency and dominant tropes of deviance and transgression may provide discursive tools to open further spaces of options and conditions of possibility for HIV positive women in Vancouver’s inner city.

On a different level, the research is also about trying to challenge conventional methods as well as the scope of subject material in bioethics. Feminist thought in this field has drawn attention to chasms between abstract principles and constructs of the liberal philosophical tradition that are employed within dramatic case-based scenarios of life and death and material, routine, and embodied ways in which health care actually occurs (Lindeman Nelson 2000; Shildrick 2008). Additionally, there has been recent movement amongst feminists working in bioethics toward taking seriously analyses of critical cultural studies, poststructuralist, and postmodernist thought, which prioritize the quotidian, utilizing tensions and contradictions of daily lived experience as an entry point into theorizing about concepts such as agency. To my mind, these latter insights have not been adequately carried through to ethical thought in a vast array of health-related discourses, including public health. Nevertheless, there may exist an affiliation for one another, given that each shares concerns about material conditions as they are lived by individuals marked as different. In an effort to theorize this kind of potential affiliation, I discuss further on how HIV care in Vancouver’s inner city sits at the intersection of individual biomedicine and population health and use the work as a whole to offer an analysis of ethical considerations within this intersection.

In Chapter One, I juxtapose a dominant or conventional narrative of the history of the HIV/AIDS epidemic and current challenges relating to treatment access in the Downtown Eastside community with narratives offered to me from physicians, nurses, researchers and importantly, women living with HIV/AIDS. These situated, embedded stories of HIV/AIDS in the community expose some of the places where a dominant narrative makes broad strokes and
general claims, which sweep away particularity and, I argue, reinforce the stereotypical thinking of the community. In addition, I give a more detailed historical and political context to the epidemic, in order to motivate the trajectory of my analysis and gesture toward ways in which these empirical and philosophical issues hang together. I begin to outline my argument that standards and ideals of liberalism, which operate within biomedical knowledge and practices, function as an invisible normative scaffolding that rationalizes treatment options and understandings of those who attempt to engage in HIV care, structuring possibilities for women’s agency.

In Chapter Two I give a discussion of liberal humanism and its presuppositions regarding agency and “the self,” in order to demonstrate how these ideals are embedded in conventional ways of thinking about adherence to ART. I explore this further in Chapter Three, through my examination of the conventional adherence research practices in epidemiology—asking and answering what sort of knowledge these practices are able to construct around the phenomenon of adherence to ART. I argue that conventional research discourses construct non-adherent patients as a social “kind.” In addition, I offer to the reader my own methods of study and suggest how these might bring to light some lesser-known, hidden, and elusive aspects of adherence.

With respect to HIV/AIDS discourses and adherence to ART in Vancouver’s inner city, medical research and practice are interrelated. In Chapter Four, I return to an examination of the medical system and multiple and various ways that adherence is understood in it, depending on the interests, purposes and rhetorical spaces of those who employ the concept. But this leads me to question why, given the diversity of objects and practices that make up “adherence,” there is a dominant narrative; the answer I offer implicates the normative scaffolding of rational actors and rational autonomous agency. In Chapter Five I take this body of thought as the foundation for the argument that social identities shape, and are shaped by, medical discourse and practices of
HIV care and with the qualitative data of 15 months of participant observation and numerous interview with patients, health care providers and researchers in the community, I offer an alternate view of non-adherence to ART.

This alternate view pushes against the taken-for-grantedness of liberal understandings of autonomous agency and the self. Chapter Six explores this more carefully, taking non-adherence to be a mode of agency that exists in relation to normative standards of liberalism operating in biomedicine. This discussion leads me to suggest in that the use of the term “agency” to designate a kind of power or capacity requires an ontologically relational, rather than individual, understanding of autonomous agency and of the self. In Chapter Seven, I examine relational accounts of autonomy and use a feminist (relational) reconfiguration of autonomy to mark out a number of issues with respect to adherence and medical care that feminist bioethics ought to grapple with.

To conclude, I return to the issue of the scaling up treatment in Downtown Eastside Vancouver, which is promoted both as sound clinical practice and as a means of preventing new infections. As questions regarding the logistics of treatment in the community continue to be investigated and proclamations of rights, ethics, and scientific evidence given, there is a pressing need for researchers and policy makers to pay attention to those who are left behind and left uncounted by the conventional approaches to studying adherence to ART. This requires a robust critique of the normative frameworks upon which medical research, clinical practice, and health policy function.

…blind men such as we are in these days have only the choice between surrender and adventure. And yet we cannot avoid the duty of determining here and now the attitude to adopt with regard to the present situation. That is why, until we have—if indeed, such a thing is possible—taken to pieces the social mechanism, it is permissible perhaps to try and outline its principles; provided it be clearly understood that such as rough sketch rules out any kind of categorical assertion and aims solely at submitting a few ideas, by way of hypotheses, to the critical examination of honest people.

(Simone Weil 1955, trans. 1958, 58-59)
CHAPTER ONE
THE BANALITY OF CRISIS

I heard about Carly∗ before I met her. I had begun to carry out research at one of the community clinics that provided care to individuals in the Downtown Eastside community and it was here that her name was mentioned. She was off of her medications again, though still participating in an adherence intervention study and receiving the weekly honorarium that was meant to be tied to her following through with therapy. We met in person in January 2008, during one of her hospital stays and seemed to get along well. Perhaps she simply needed someone to talk to. At any rate, we began to carry out life history interviews in March 2008. Over the course of my research within two of the community clinics that provide care to individuals living in the Downtown Eastside, and then later carrying out aspects of the qualitative research study with Carly herself, it struck me that, on a good day, she would be described by health care providers, social workers, and other staff as being “feisty”; alternately, she might be called “a handful,” and once (to me, out of her earshot) “a piece of work.”

More pejorative descriptions would come at times when Carly was frustrated by the clinic and hospital staff she encountered, as she rarely hesitated to let them know this, sometimes to her detriment. On more than one occasion, I was with her when a warning was issued, that she needed to start behaving, or she would be asked to leave. Her long-time partner would likewise admonish her when she would loudly criticize the long waits, perceived favoritism in clinical settings, and what she took to be unfair or disrespectful treatment. “Cut it out,” he once said, “or you’re not going to get in [to see the doctor] at all.” His comments echo the

∗ All names have been changed in an effort to maintain confidentiality. In many instances, as with Carly, I asked individuals how they would like to be referred to in writing about the research. While many professed to be comfortable with having their names included, I pressed the issue, concerned about their privacy, for a number of reasons. Carly and a number of other women who took part in the project picked nicknames that were important to them. Although they may potentially be identifiable pseudonyms, it was a kind of compromise between us, with respect to my concerns about their privacy and their very legitimate insistence that they be able to tell aspects of their life stories in ways they saw fit.
sentiments of one of the physicians I worked with over the course of the project. Talking about how people from the eastside were treated within area hospitals, she said to me, "Oh yeah. The difficult ones always get screwed." Many of the health care providers considered Carly to be well-known for hustling any and all aspects of health and social service systems—she would and could, they seemed to believe, move mountains if she so desired. It surprised me that for the length of time she’d lived in marginal housing in the community and for as ill as she was, in and out of hospital the entire 18 months that I knew her, various hospital and clinic staff she interfaced with did not seem to consider her to be particularly vulnerable or disadvantaged.

Carly had been living with HIV for nearly fourteen years when we met. She was sensitive to how she was perceived by people she took to be ‘straight,’ those working in regular jobs: support workers, health care staff, people who didn’t have substance use issues. “Normal people,” as she often called them. She would regularly become angered while telling me how ignorant “normal people” could be; they treated her with disrespect, always assuming the worst about her. Carly tied these attitudes to her living in Vancouver’s inner city, where she felt that negative judgments are generalized across community members, who were presumed to all have addictions and live on social assistance. These stereotypes and stigmatizing attitudes hit a nerve, being attached to her own challenges with drug use over the years and her dependency on disability benefits; HIV was just one more thing in her life to indicate how she continued to “mess up,” a characterization that she herself gave, feeling it to be shared by wider society.

She had begun using heroin when she was thirteen years old and had become infected with HIV from injecting practices in her early twenties—sometime in 1994, she figured, during the peak of the HIV epidemic in Vancouver’s Downtown Eastside. Talking about finding out her HIV status she said:

*I got it when I was 22. I think back, 22 years old and my life got taken away from me...well, that’s not quite true. I’m still here. [ha] Famous last words... I didn’t know how to quit [drugs]. And now I’m suffering the consequences. 22 and your life’s been*
taken away because you trusted somebody... You have a feeling, you don’t know for sure, next thing you get the results and you got it [HIV]. My sister said to me, you’re going to get it. I’m like, ‘no I’m not’ and then at 22 I get it and she’s saying, ‘I told you so. You go around using drugs, you get what’s coming to you.’ And then you face the consequences...

Considering my life and how I was raised, I’m condemned already. And then you find out you got it...

Life’s not fair when you’re a drug addict. I was 26 the first time I was on meds, in Kelowna. It was big hush hush thing then. You were the plague. Nobody would talk to me, no friends... then I moved back down here [the Downtown Eastside]. Basically you’re seen as the devil’s child. Then, I thought my life was over. People condemn people right away. They don’t even give you a chance, see that you can change. It’s just like with welfare, fighting over socks and underwear because they [the previous housing society] threw all my stuff out. What bothered me was them throwing it away without telling me and throwing away the pictures. They just assume because you’re [an addict] that none of that stuff matters. They condemn you without even knowing.

Carly was afraid of pain and of dying, telling me that deep down she was a softy, even though most people “think I’m a bitch.” She had a tough shell. She had lost a number of friends in the community to overdose deaths, suicide, and health issues, and remarked that these losses had seemed to be increasing over that first year we had gotten to know each other. In our conversations she often wondered why it was that so many of her friends had died, leaving her behind. She would ask, “why not me?” and tell me that she figured it wasn’t her time yet. Early in July 2009, it was her time and she passed away quietly late one night after a particularly long hospital stay that had been fraught with seizures, decreased level of consciousness, and painful edema and ascites.

THE CONVENTIONAL ADHERENCE NARRATIVE

These brief glimpses into Carly’s life gesture toward important but disparate issues that are connected to women’s experiences of HIV care in Vancouver’s inner city, issues that I argue are crucial to understanding the statistics surrounding gendered disparities in HIV treatment in the community. Having started antiretrovirals (ARVs) for the first time at age 26, Carly was on and off of medications until she passed away from complications of Hepatitis C and HIV at age
36. This may seem like a representative case of non-adherence by a woman who would be classified in the standard medical literature as Aboriginal (she was half Cree), an injection drug user (IDU), as well as a female sex worker (FSW), as she had been (at times) involved in sex work. Predominantly, figures relating to treatment for HIV within the community suggest that women in the inner city constitute a “hard-to-reach population,” who are not enjoying the advantages of HAART due to challenges with accessing care and remaining adherent on medication regimens. Although the absolute number of women infected with HIV in Canada remains lower than that of men, limitations surrounding women’s access to, and continuity of, antiretroviral therapy (ART) have been consistently documented through epidemiological research, particularly in the Downtown Eastside community. These disparities have been linked to gender inequality, the sequele of drug addiction and mental illness, the frequency of post-traumatic stress disorder, as well as increased toxicity and medication side effects in women.¹

Amongst impoverished urban communities, women are less likely to receive antiretroviral therapy and those who do start are more likely to be hospitalized, regardless of drug regimen (Fielden et al. 2009). Recent calls to expand HIV treatment in the Downtown Eastside are likewise portrayed in terms of limited access to services and similar psychosocial barriers to receiving care.

Carly was taken by many people in the community clinic and hospital settings to epitomize the hustling, manipulative trope of a drug user—just the kind of person who has limited access to health care and who is non-adherent to therapy. Along with the numerous ways in which Carly could be grouped according to categories of people who are understood to be predictably non-adherent to therapy, her non-adherence can also be understood along conventional lines of thinking about health behaviours and decision-making. Commonly, clinical research practices approach non-adherence in terms of health behaviour models, which attempt to explain and predict health decisions and actions (such as adherence) based on attitudes
and beliefs of patients, presuming a fairly direct pathway from motivation to intention to action. Following medical advice properly is understood to be rational (Conrad 1985) and similar to philosophical views of rational action, health behaviour theories suppose that acts of ingesting medications are behaviours critically determined by attitudes and motivation, beliefs (including information and education about illness and therapies) and expected outcomes (Munro et al., 2007). Thus, hindrances to development motivations, intentions, and beliefs are likely to increase non-adherence. This includes substance use (current and past history of), depressed mood, and diminished self-efficacy. Pill-taking and other forms of adherence are individual behaviours; “the social” may help or hinder getting a tablet into someone’s mouth, but action is ultimately done by agents, in relation to standards of rationality set by biomedicine. A substantial body of adherence literature endorses this view, inasmuch as their focus tends to be on the mental functioning of patients (mood, substance use), patients’ self-regarding attitudes (e.g. self-efficacy), and expectations and beliefs about medications and their importance to health.

It is not only the models of health behaviour and assumptions regarding the authority of health care providers’ advice that reproduce images of rational agency within adherence research. Certain variables have become popularized as explanans within HIV-related research, which themselves reinforce associations between compromised rationality and non-adherence to treatment. Carly was seldom believed when she self-reported decreasing her drug consumption and presumptions of drug use led to expectations that she would be non-adherent to therapy. She had been prescribed methadone and antiretrovirals during the fall of 2007 and had not been taken them. Her reputation did not bode well for her health care providers’ expectations of her, regardless of her own confidence and interest in treatment. Thus when she asked her physician at one visit about re-starting medications, it was suggested that she might be better off to wait until she was more “stable.” Her physicians and nurses wanted to see that she could institute
various changes before they were willing to engage with her—recommendations were made that she think about going back to see the drug and alcohol counselor, that she try harder to pick up her methadone script on the same day each week and from the same provider, rather than coming in when it was convenient for her.

It is possible to see here how health behaviour models are applied in practice—drug use meant she wasn’t appropriately motivated or did not have adequate insight into her health-related ends and the means to achieve them; her physicians’ outcome expectancies, based on their own view of her past history and her current behaviour, standing in place of her own. But what is interesting is that in the ten years during which she had numerous starts of HIV therapy, there was in fact one long period of “near-perfect adherence.”

Carly was also on and off of methadone substitution therapy for her longstanding heroin use, and by her estimates, was seeing a doctor often more than once a week regardless of the medications she was currently taking, particularly in the last year of her life. She had also decreased her drug use and was living in relatively stable housing with her partner. So aside from being “engaged” in the health care system, she was in the midst of making an application for her own room in the same building and they had started to pay back a number of long-standing debts.

A DIFFERENT KIND OF NARRATIVE

Her story, for as much as it can be understood through conventional adherence discourses, also stands in contrast to dominant depictions of women-as-hard-to-reach and drug users as not engaged with the system. Consider for a moment the term barrier. It evokes an image of something that is intended to restrict movement; it suggests blockade, something that impedes or hinders action. Within the medical literature, an emphasis on barriers translates to why individuals fail to engage in the health care system; those that are grouped according to barriers are then conceived of as a “hard-to-reach” population. Analyses then logically focus on issues such as pragmatics of substance use. For example, studies ask about sleeping through
appointment times, being incarcerated (Kerr et al., 2004; Small et al., 2009), the proximity of health services to known locations of police crackdowns, as well as the presence of dealers, pimps and johns in clinic waiting rooms and nearby locations (Shannon et al., 2008, Kerr, Small and Wood, 2005). As important as these considerations might be, they nevertheless shift an analysis away from the effects of the quality of health care interactions on continuity of HIV care, interactions that are documented to occur. This may, depending on choices of language and issues, dehistoricize, and depoliticize aspects of the health care system, which shape the trajectories of HIV care.³

Like many other women living with HIV in the community, Carly had regular interactions within the medical system, including participation in a number of HIV support programs. For her, as for the other women I worked with over the course of my research, challenges with sustained, effective engagement in HIV care were not merely a matter of access. Nor were they, as I shall argue throughout, reducible to substance use, mental illness, or cognitive capacity. With that, allow me to employ Carly’s narrative in creating the discursive space to ask four questions, which guide this project. First, in arguing that conventional measures of access and adherence fail to capture important elements of adherence to ART, it seems pertinent to question what other methods might be suitable. Therefore I ask, what does an emphasis on lived experience of HIV/AIDS and its treatment within Vancouver’s inner city reveal about adherence to ART? My research will demonstrate how patterned disparities in HIV care, whereby women in the community have been historically less likely to receive ART and those who do begin treatment are less likely to continue on it, are part of gendered and racialized dynamics of daily struggles of urban poverty in Vancouver’s inner city—these struggles are part of a much longer history and wider expanse of oppression that are continually shifting aspects of the fabric of contemporary Canadian society and not merely a set of independent and clearly delineated “barriers.”
In her telling me about her life and about living with HIV/AIDS, Carly emphasized the role that stereotypes and prejudices toward substance use, substance users, and Aboriginal persons play within medical settings as well as within the wider community where health services exist. She felt she was seen as just an addict and that her substance use dictated responses people had to her, guiding what actions and interventions were considered appropriate, particularly when she was not prepared to sit quietly or act agreeably. Her sentiments aren’t entirely off base, corroborated to some extent by the physician quoted above, who described the so-called difficult patients as the ones who “always get screwed.” Carly also described how being Aboriginal and living in Downtown Eastside Vancouver meant that she felt she was even farther removed from those who she described as “normal.” Linking the issue of images and stereotypes based on social identity with the previous question, we might also ask, what are effects of continuing to employ conventional measures of access and adherence? That is to say, it is necessary to examine whether and how conventional measures may inadvertently reinforce notions of certain social identities as transgressive, which then influence the trajectory of HIV care in the health system.

One task of philosophical analysis is to examine how descriptions having bearing upon our thinking about particular issues in a given social field and about those who make up that social world. As I examine in the following chapters, the epistemological stance of conventional modes of investigation employed in adherence research (namely, social epidemiology) prioritizes a causal/predictive biomedical rationale. This rationale is foundational for conventional medical models—appealing to many for its focus on somatic manifestations of disease and organic mechanisms of action of pathological processes (Engel 1977; McLaren 1998). A reductionist logic of cause-effect relationships makes otherwise complex social phenomena amendable to rationally designed therapeutic interventions, hence the appeal for those experts who are able to wield tools of bodily restitution.
But a reductive logic also shapes how we think about non-adherence as an issue and patients who are non-adherent as persons. As objectivist models of thought, the epistemological stance of conventional adherence research methodologies is “detached from the particularities of time and place, from personal quirks, prejudices, and interests, and most centrally, from the object itself” (Bordo 1986, quoted in Code 1991, 51). In this project, I challenge conventional adherence discourses on two counts: first, that a detachment of conventional adherence research from the particularities of health services within different spaces they operate in, and from historical and social particularities of various actors involved, fails to capture meanings embedded within acts of ingesting medicines. Second, that in so doing, objectivist modes of thought reinforce pathological tropes and ascribed identities of those under study.

This last statement brings to the forefront of the project an interesting issue: why ought we think of ingesting medicine as an activity that is connected to systems of meaning and signification, which are (inherently) social? A biomedical view of pill-taking is decidedly that of a means-end relationship—one takes one’s ARVs in order to suppress viral replication and diminish the impact of HIV on the body—pill taking brings about “health,” which can be measured by plasma viral load and CD4 count as well as inferred by the presence or absence of co-morbid conditions such as opportunistic infections. In contrast, Carly’s description of HIV being something that she had “coming” to her, describing herself as being seen as the “devil’s child” point to a much thicker understanding of HIV infection as an illness with a particularly powerful cultural significance.

Understanding ways in which pathological processes are simultaneously cultural processes is old hat in medical anthropology and sociology; this is certainly the case with HIV/AIDS. Arthur Kleinman, for example, describes HIV/AIDS as having powerful symbolic loading, in which a double standard of amoral sexuality/individual rights functions on the one hand, while a hypocritical condemnation attached to HIV/AIDS functions on the other. As a
diagnosis, it confers the stigmata of venereal sin (Kleinman 1988, 21-22). Consider also that conventional statistical adherence research regards non-adherence in terms of “risk,” risks which are analyzed following the same demographic categories and drug use pattern measures as that of HIV incidence itself. The connection between characterizations of individuals who might be called “predictably” non-adherent and a presumed culpability of having acquired HIV/AIDS is not insignificant. Risk of non-adherence tracks along lines of risk of HIV itself, one inscribing deviance and transgression upon the other. Thus treatment of HIV/AIDS shares some of the symbolism of contamination, pollution, and moral risk.

I shall suggest that such joint significations are connected to a wider set of social imaginaries related to identity categories that police the boundaries of marginality. Lorraine Code describes social imaginaries as being, “about often-implicit but nonetheless effective systems of images, meanings, metaphors, and interlocking explanations-expectation within which people, in specific time periods and geographical-cultural climates, enact their knowledge and subjectivities and craft their self-understandings” (Code 2006, 29). Social imaginaries are complex scenes, normative notions, and ideas with social, historical, material and political foundations; they make up a basis for individuals’ understanding of their social existence, allowing them to make sense of themselves and others in society (Vogler 2002; Taylor 2002). As both moral and psychic space (Cornell 1995; Cornell 2007), imaginaries hold conceptual frameworks in place and are part of one’s lived experience by virtue of an ability to maintain legitimacy of certain interpretations of experiences in the world, while discrediting others (Code 2006, 22).

Throughout, I emphasize how social imaginaries related to rational autonomous agency conflict with imagistic content of identity categories that are applied to substance-using women, influencing possibilities for action within various locations in the health care system, as well as meanings attached to HIV infection and its treatment. Qualitative studies that explore
relationships between meaning and non-adherent behaviour indicate that what appears to be non-adherent from a biomedical/allopathic medical system perspective may be logical within constraints of day-to-day life (Kleinman 1981; Levy 1983). Likewise, ethnographic research examining women’s adherence to ART also highlights ways in which adherence is part of complex systems of social action—women report that medications act as daily reminders of their sickness, lack of normalcy (according to societal standards), limited control over their bodies and failure to achieve health (Roberts and Mann, 2000). There is also a wide body of literature relating consumption of ART to experiences of HIV-related stigma. But attempting to place “stigma” on a quantitative survey in order to generate a measure of its contribution to non-adherent behaviour often misses ways in which phenomenon is itself multiply and variably experienced. This mischaracterizes stigma (the experience) and stigmata (the identifying characteristic) as individualized, borne by an object of research, rather than understanding it as intersubjective phenomena.

As I discuss in Chapters Four and Five, pill-taking is “symbolically loaded” in a variety of ways, as are other actions within the health care system that might reasonably be thought of as forms of adherence to HIV care (including remaining in hospital after an admission, making and following through with medical appointments, requisitions for blood draws, chest radiographs, and so on). Quantitative studies are limited in the extent to which interpersonal and institutional dynamics are explored within their analyses, mainly due to constraints of statistically-oriented methodologies. By pointing to a variety of players who are part of the landscape of HIV care in Vancouver’s inner city, the brief vignette begins to substantiate a qualitative approach to conceptualizing pill-taking, medical advice giving, etc., that emphasizes intersubjective phenomena. My perspective, therefore, sits juxtaposed to conventional analyses of non-adherence in a further way: I argue that in order to understand adherence to HIV therapy, one must understand how patients and health care staff interact within non-profit as well as health
authority clinics of the community, hospitals, corrections system and housing units. The significance of such interactions cannot be adequately examined from a framework of methodological individualism.

Although it is not uncommon for epidemiological literature to conceptualize certain findings as “structural” aspects that are challenges for maintaining therapeutic regimens, these are frequently conceived as a kind of outer ring of factors, methodologically separated from interpersonal interactions. “Structure,” on these accounts, is treated as a different level or sphere of activity. Instead, I suggest that “structural” aspects of care need to be understood as having mutually investing relationships with discursive and material aspects of lived experience, including various theoretical affiliations and interests of biomedical research and practice.

Social structures and institutions do not fall from the sky as pre-fabricated units—their workings, ideologies and processes must be produced and reproduced through concrete materials and actions. My own approach will be to try to forge linkages between particularized, concrete experiences with higher-level policy and programming that make up “structural” forces.

For instance, we might think of how administrators in the Health Authority and policy makers at various levels of government are part of the structuring of the health care system and how their actions and decisions shape day-to-day experiences of care and, through that, health outcomes. A number of nurses and physicians working within the clinics of the Vancouver Coastal Health Authority have reported to me that the requirements of the new electronic medical record system, PARIS, will mean that they have less face-to-face time with patients and in some instances will be required to decrease their patient load by fifteen percent. Said one physician:

*It sucks. It does, really, nothing for us besides irritate. But it does apparently...they [administration] can do the stats better and research better. The prescription module doesn’t do what a good program should [and] the additional time spent here [at the computer] has to be taken from patients. There’s how it [impacts].*
A community nurse likewise described it as working well for “the bean counters and the bureaucrats,” but not those working on the ground. By virtue of its ability to alter the scope of health care practices and direct the actions of the human actors (nurses) who interact with it, we need to understand the PARIS system as a non-human actor in this particular social field. Relationships between various actors (human and non-human) are necessary for understanding impacts of administrative policy and programming—an impact of an institution—that has actual effects on the use of health care providers’ time and ability to contend with their patients’ health concerns.

Of course, in thinking about this as an issue for health care delivery, it is possible to question whether or not this is problematic ceteris paribus. Improving infrastructure at the top of the health system may be a legitimate balance against face-to-face time, but as I will examine shortly, the balancing act that favours administration and management is part of a longer history of actions within the health care system that prioritizes a biomedical rationality, reinforces problematic power dynamics between health care providers and patients, and marginalizes expertise of those who have worked on the frontlines of health care in the inner city community (likewise for patients, of their own experience). Thus, decisions and policies within the health system are not discrete events, separated from issues surrounding what is conventionally considered to be part of adherence to ART, nor are they detached from a historical milieu. Producing this sort historically and politically embedded analysis is not really possible if one is preoccupied with achieving statistical significance. In contrast to views of adherence to ART that merely examine whether, how and under what quantifiable circumstances a pill is swallowed, my own empirical work connects pill-taking with a host of other complex social actions, including the intricacies of substitution therapy for addictions, hospital stays, health care policies, and interactions with other institutions peripheral to the health care system.
To carry on this mode of thought: as a communicable disease, HIV care is linked into wider system of surveillance and intervention under the auspices of the public health authority; as an epidemic of Vancouver’s Downtown Eastside, surveillance extends through to other arms of the state, including those linked to public housing, social assistance and disability, and the Ministry of Children and Family Development. In addition to frequent medical interactions required of HIV/AIDS care, residents of the Downtown Eastside contend with some form of state authority in their daily lives; various elements construct the area as an institutional ghetto, reinforcing a need for surveillance and intervention as urgent. Leslie Robertson and Dara Culhane write of women living in the community, “They live in a milieu significantly ordered by health and social services, wherein their narratives provide cues for diagnoses or for the implementation of policies that greatly influence their lives” (Robertson and Culhane 2005, 9). Rethinking antiretroviral adherence requires an analytic lens that extends beyond outpatient and ward settings. It becomes pertinent to ask, *if adherence is, in fact, a complex set of actions informed by one’s social identity, what elements shape contours of agency in clinical settings where HIV care occurs?*

One element that is crucial for understanding adherence to ART are roles played by social identity in relation to idealizations of personhood widely accepted within modern affluent western societies. Women’s narratives are too often understood in terms of social identities ascribed to them through statistics and demographics—IDU, FSW, Aboriginal versus non-Aboriginal. Taking up feminist perspectives on agency and the self, I contend that dominant stereotypes and conceptualizations of women living with HIV in the Downtown Eastside community are buttressed by a pervasive fiction of an ideal liberal humanist agent/self: a masculinized self who is rational, maximizing, unified, and motivationally transparent. This view of the “self” is one that tropes of drug users, Aboriginal people, and “women” in general, are held in opposition to.
Aboriginal women in particular are seen as needing to be “engaged” and brought into the health care system so that they are no longer elusive to the medical system; no longer non-adherent and a potential contributor to community viral load or a risk to public’s health. Historically, imperialism has invoked morality as well physicality in determining a need for a colonial pastoral power—insofar as HIV “risk” literature invokes notions of venereal sin, morality and health continue to be imaginatively linked; all the more so when “risk” is connected to images of non-white, non-male, Others who have been imagined to represent the irrationality of “nature.” I utilize my empirical research to point to some ways in which presumptions of deviance of women from a supposedly neutral standard supplied by a liberal intellectual tradition are reflected in health policy and treatment decision-making. Inasmuch as an idealized liberal humanist agent serves to maintain dominant narratives of HIV positive women living in the inner city as deviant, their marginal positioning is maintained.

It is this problematic construct of “self-as-rational-agent” that drives what I take to be troubled conceptualizations of autonomy within bioethics discourse and, as I shall argue, conventional views of adherence. Non-adherent patients undertake actions that remove them from structures that are set up to guide their actions. Idealizations of the “self” are part of a moral and emotional structuring of the health care system, thereby shaping women’s experiences and impacting adherence to ART. Thinking about non-adherence to ART provides, therefore, a model system by which to examine limitations of traditional liberal philosophical concepts such as rational autonomous agency—the challenges I will raise with conventional approaches to understanding non-adherence parallel challenges in much of the conventional liberal philosophical discourse. My aim is to enter into dialogue regarding action and agency on the one hand and adherence on the other, taking seriously poststructuralist insights regarding social identity, subject position, and relations of power.
Following through on an analysis of the contours of agency in the health care system means we must ask a fourth and final question, how are we to understand a host of concepts related to agency, including autonomy and responsibility, under this different picture of adherence? For example, I contend that a reliance on idealizations of liberal humanism mean that conceptions of autonomy operate in a number of conflicting ways in this setting. Declarations by health care providers that an individual’s action was “autonomous” justify non-intervention in a health-care decision process and often, removal of health services. Meanwhile, the depiction of widespread cognitive failures (be it from addiction, mental illness or trauma) justify paternalistic approaches to managing individual patients as well as public health concerns. What unites these conflicting views is this: where a person’s decision to reject treatment is deemed “autonomous,” an ascription of a deviant or transgressive identity is strengthened, for not following through on what would be a rational choice (to take medications or to remain in hospital, for example). This serves to exclude such individuals from “polite” society. Where people are seen as being ever more irrational, strong paternalism becomes an alternate response; this also excludes those subject to strong paternalism on the basis of non-agency. I draw on problems of adherence to ART as an entry point into a critique of autonomy as it is so often employed within bioethics, linking presumptions about what kinds of people are considered autonomous to ways in which surveillance, categorization, medicalization, and biomedical rationales in HIV research and care shape spaces of possible action for women.

THE BANALITY OF CRISIS: CHAPTER OVERVIEW

This chapter functions in two ways: it provides a broader view of historical and political conditions within which received wisdom regarding ART and practices of HIV care in Vancouver’s inner city operates, while organizing the philosophical concepts that I employ throughout the research as a whole. In the remaining sections, I describe aspects of historical and political contexts of a current range of HIV services in Vancouver’s Downtown Eastside,
linking these to experiences those who participated in the fifteen months of qualitative research I carried out in the community. Such contextual features will orient the reader to some lesser-known aspects of an area that is highly visible and much maligned, while making clear how ingestion of medicines and participation in or withdrawal from health care services are highly complex social actions, shaped by history and politics.

Over the course of the dissertation, I shall argue that understanding adherence to HIV care requires an understanding of how these institutions, their representative agents, and patients interact with each other, within a context of competing ideologies, wider social conceptualizations of HIV infection, substance use and urban poverty, and the political climate of British Columbia, Canada. These are questions that cannot be inferred from conventional measures of access and adherence to HIV care, which are oriented around an epistemology with universalist presuppositions. I link my discussion of gendered disparities in HIV care to a set of intersecting philosophical questions that form a basis for an alternate reading of women’s adherence to ART. Departing (epistemologically and methodologically) from received views of adherence to care being a matter of motivation, self-efficacy, rationality, and will, I suggest that we revise our analysis of the actions (and non-actions) that make up adherence (and non-adherence) to therapy and medical advice, tying such actions into larger issues of social identity, agency and autonomy, as conceptualized outside of a traditional rationalist paradigm.

This analytical approach, as well as my recognition of the need to examine relationships of authority, expertise, identity and agency, drives my interest in the “banality” of the HIV epidemic in Vancouver’s Downtown Eastside, as suggested by the chapter’s title. Emphasizing banality is not to minimize effects of HIV infection on women’s lives, but to point to ways in which this is a crisis that has played out on a daily basis for more than twenty years, with an extensive number of roles for various actors and institutions. The notion of banality is also a strategic choice of rhetoric I employ in order to suggest that an analysis of disparities in health
must be concerned with how such disparities come to be lived on a day-to-day basis. The banal, the mundane, the routine—these are loci within which micro-processes of power and privilege operate, thus they are the focus of my attention through much of this dissertation.

I expect that it is becoming clear how a host of canonical issues for feminist bioethics are relevant to this project. Although HIV care is in no way exclusively in the domain of women’s health, insofar as I read disparities in the use of HIV health services as a product of a racialized and gendered social field, such disparities stands out to me as a pertinent issue for feminist bioethics. Feminist theorizing about health and illness need not be relegated to the domains of reproduction and its associated technologies; similarly, feminist theorizing about the self, agency and autonomy ought also to avoid the trap of essentialism—care giving roles, objectification and vulnerability to violence do not make up the full range of female experience, nor are these topics the only philosophical substrates for feminist thought. The methodological approach of this work is an additional feature of that aligns my research with feminist interests in bioethics. In pointing out important connections between epistemology, methodology, and research method, Sandra Harding asks whether there is a distinctive feminist method of inquiry (Harding 1987, 2-3). In a similar vein, Diana Meyers asks how feminist politics can survive the diversity of women’s experiences, shaped by race, class, ethnicity, sexual orientation, as well as gender (Meyers 1997, 1). This project offers a tangible answer to both of these theorists.

The empirical research I present utilizes self-reflexive qualitative methodologies, including participant observation and open-ended interviewing, located within an interpretive theoretical stance that attempts to give as much priority to interpretations, insights and influence of the women participating in the project as it does to my own. As a political endeavor, feminist engagement in bioethics ought to engage the multiple, contradictory, and partial ways in which actual people actually experience health, illness, and the like. Both the theoretical insights and research practice presented here are congruent with this stance.
HISTORICAL CONTEXT: SILENT TURF WARS AND MICROPOLITICS

The following pages offer a thicker view of temporal and spatial aspects of HIV care in the Downtown Eastside community—not only who the “players” are now, but who they have been; where care is accessed, how these spaces have changed over time; and relationships between these elements and British Columbia’s political climate over the course of the HIV epidemic, as it unfolded in this particular community. In taking a more historically nuanced approach to HIV care, I suggest that findings implied by a large body of medical research and reported by lay press, namely that non-adherence to therapy is an issue of lack of access to services and/or barriers to care due to personal drug use, mental illness, as well as the effects of community violence, fail to capture how institutional aspects of HIV care have developed and the significance of institutions on interpersonal dynamics when engaging in the medical system. By employing mechanistic language of causal and associative factors, such discourses also restrict the range of relevant considerations within the field. They fail to examine conditions that may contribute to a climate where non-adherence is in fact a reasonable action for patients.

I. GROUNDWORK FOR AN EPIDEMIC

In contrast to the latest calls for action that have accompanied conventional understandings of the limited uptake of HIV treatment in the Downtown Eastside community, a number of physicians and nurses emphasized to me how health services have been delivered by a host of frontline staff since the early days of the epidemic. Discussing with me widespread interpretations of morbidity and mortality data regarding untreated HIV infection in Downtown Eastside Vancouver, a physician who has provided HIV care in the downtown community for a number of years stated, “[researchers] show up there, acting like Christopher Columbus, ‘oh, there’s a problem in the Downtown Eastside, these people aren’t being treated...’” He went on to point out that, in fact, people are interfacing with the system at various times, in a variety of spaces, and many have done so for a substantial period of time. Initially, care was palliative,
later based on mono- and dual-therapy, and finally triple combination therapy in 1996. Outreach programs had also begun by the start of the 1990’s, from the ground up, primarily within sites that were at arms length from the Health Board. Well before the Vancouver/Richmond Health Board’s (V/RHB) declared a public health emergency in 1997 due to rates of HIV infection in the Downtown Eastside, and prior to the Ministry of Health’s “Framework for Action on HIV/AIDS,” the first strategic plans to address the HIV epidemic in the Downtown Eastside were developed by and through community organizations who had come together, frustrated by the lack of coordinated movement at both levels of health governance.

As a director of nursing working in an HIV care setting in the 1980’s and early 1990’s explained to me, there was a recognition in the mid-80’s, amongst those working in the community, that they had “all the co-factors” for an epidemic—a geographically confined location, injection drug use, poverty, individuals dislocated from home communities—but that very little was being done at a higher level around strategic planning:

> By the late 80’s we had women who were established in commercial sex work using injection drugs and we had First Nations, who cut across gay, bisexual, drug use...it was less than 1% [from] injection drug use. From the [higher ups] it was “oh no, you don’t have anything to worry about.” Then of course by ’93, ’94, it was on its way up.

Her statement is echoed by the HIV/AIDS Legal Network: for all of the early warnings of an epidemic, little concrete action was taken higher up, until much later in the trajectory of the epidemic (Remis and Sutherland, 1993; quoted in HIV/AIDS Legal Network, 2005). What had taken place were on-going budget cut backs and a dramatic loss of hospital beds across the province. At the same time, there were “growing pains” of the regionalization of the health care system to deal with, which proved to be a challenge for instituting any kind of systematic effort or call for accountability in health governance, thus the reliance on individuals working in the community and AIDS service organizations to take up the slack.
Leading me through her experience of the trajectory of the HIV epidemic, the nursing director stated that the community response was at its most productive in the early 90’s, when “we had a community outreach office, we had our multi-di [disciplinary] committee, we had strategic planning. I mean, this was all before anything [was happening] in the health authorities or in the Ministry.” She also described the difficulties with maintaining this community-driven response, saying, “by 1995 or so and we were well into injection drug use and feeling the impact on the [medical] ward. And by that time we were raw...about what the realities were.” In September 1997, the V/RHB passed a motion declaring a public health emergency in response to reported rates of HIV infection in the Downtown Eastside, with higher prevalence among female injection drug users (IDU) than males. Although 1996/1997 was (retrospectively) identified as the peak of the HIV epidemic in injection drug users, the steep rise in HIV diagnoses related to drug use was identified to occur in 1992/1993 and as my discussions with health care providers who had been working in the community at that time suggest, individuals in the community had been bracing for the impact some time prior to that and to the declaration of the public health emergency.

For all the community-based work that had been happening prior to it, the declaration of the public health emergency was most certainly a pivotal point in the trajectory of the epidemic, spurring the Health Board to action. In many ways, this brought continued attention as well as financial resources to the community and set into motion a number of significant policy changes. The health emergency was announced just months after the proclamations of success with triple combination therapy at the 11th International AIDS Society Conference in Vancouver. The mood at the conference was described as euphoric—HIV was likened at this point to becoming a chronic disease (MacInnis 2006). The success of combination therapy meant an increase in research activities, including clinical trials, epidemiological surveillance and drug treatments offered through the BC Centre for Excellence in HIV/AIDS, and also a greater emphasis on
planning at the Ministry of Health and Health Board levels. Within the Health Board, there was a push for needle exchanges to be expanded and decentralized from one fixed site to five (and later, fourteen) sites, as well as mobile coverage (BC Partners for Mental Health and Addiction, 2003; MacPherson, 2001). Official outreach positions were established, along with expanded roles for community nursing and extended service hours at various drop-in centres and clinics run by the Health Board. HIV infection was set as a priority for the regional health authority (RHA), which continues to directly operate two community health clinics, home-based nursing programs, a mental health outreach service as well as a number of drop-in sites, while indirectly supporting various non-profit health societies that provide health services in the Downtown Eastside.

But resource allocation was also restricted in various ways and a number of health care workers in the community described to me a lack of support for particular programs and limited ability for front-line workers to impact new programming developments as the money that was available came in. For individuals working within the sites that were directly controlled by the RHA, challenges existed due to what staff perceived as the limitations of an out-of-touch system. Of one of the larger community health clinics in the neighbourhood, a physician remarked:

*It [the clinic] very much looked like, it catered to sort of an older population, chronic diseases, had city of Vancouver hours, etc. All around it was this epidemic that was happening, around all the sites and, you know, for a while there was resistance, etc. say to do methadone, to invite the real epidemic into the medical services. [But] there was, you know, money, HIV action plans happening, particularly after the AIDS conference in 1996 with triple therapy…*

Providers pointed me to a continued disconnect between the “kinds” of people administrative staff and even some physicians were comfortable with (primarily older adults living in poverty, with alcohol use issues) and those who were part of the HIV epidemic, which was heavily driven by injection cocaine. The physician quoted above described how the negative attitude toward engaging drug users in health services and providing what their health care providers sought for
them (e.g. methadone) continued for quite some time. Providers also suggested that advocating for changes in clinical practice, to meet changing needs of the population, were not well received.

The disconnect they described, between those on working on the ground and those seen as “higher up,” became exacerbated by an increased emphasis on managerial accountability for health expenditures, particularly as health care delivery continued to be reorganized. The same physician continued on:

*During that time the health authority was changing as well. It was going from the Richmond Health Board to Vancouver Coastal and all of those changes. Administratively, it was a huge big grid that keeps getting bigger with administration. So they’re doing their planning up there and all the front line people [were] still doing their [work]... the folks [who ran the programs] weren’t really asked... I mean, there were meetings and stuff but they [administration] didn’t listen to the front line folks who knew what they needed.*

The views of health care providers in the community, like those described above, demonstrate that the lack of consultation and top-down approach within the changing health care system has been felt to be a frequent aspect of health politics in the province. As I describe further on, these political maneuvers can be said to be reflective of systematic and interlocking ideologies of neoliberalism, individualism, and rational action. Moreover, the argument I develop through the body of this work contends that the latter, particularly idealizations of rational actions and rational agency, are part of the underlying dynamics of non-adherence to ART.

II. CHANGING POLITICAL ENVIRONMENT

Program implementation was taking place during two periods of health reform in the province. The first major reform was launched by the New Democratic government in 1993, following the Royal Commission on Health Care and Costs—“New Directions” initially mandated the formation of Regional Health Boards and Councils, emphasizing cost-savings through ambulatory and home-based care, as well as participation by citizens within the health system. Community responsiveness to local health care needs was explicitly connected to an
intent to build constituency support for health, broadly understood in terms of services as well as social and economic conditions (Davidson 1999, S35). This was halted in 1996 for cost assessment and later continued on under the banner, “Better Teamwork, Better Care,” albeit with an emphasis on delivery of service and accountability of boards and councils to the Ministry of Health (Davidson 1999, S36), as opposed to the earlier focus on greater public participation in health care decision-making.

While early reform had attempted to adopt a community health approach, lining up ideologically with the grassroots community development work taking place, this perspective was set aside in the interests of cost-effectiveness, concerns about efficiency within a two-level system, lack of control over the process of health expenditures by Health Board managers and the provincial government, and a desire for accountability with respect to provincial monies, rather than accountability to communities for health outcomes (Frankish, 2001). Within this revised ideology, changes in the structuring of health continued with a renewed focus on efficiency and accountability—fewer health regions, integration of services, and performance contracts were part of this reorganization. Overall, regionalization saw a simultaneous de-concentration of power (in terms of Ministry authority over health services\(^1\)) and centralization authority and control within the RHA (Frankish 2002), along with diminished roles for other local agencies and service providers.

A combination of centralization and decentralization of services was well under way at the time of the 1998 publication by the Ministry of Health/Ministry Responsible for Seniors’, Framework for Action on HIV/AIDS. Framework for Action describes the role of the Ministry of Health as setting the policy direction and priorities for HIV/AIDS as well as funding health authorities to delivery and coordinate HIV-related services, including surveillance, testing and outreach services coordinating by the BC Centre for Disease Control, research within the BC Centre for Excellence in HIV/AIDS, needle exchange programs, and other community-based
programs (BC Ministry of Health and Ministry Responsible for Seniors 1998). Health authorities were to fund a continuum of HIV/AIDS services, with an expectation that so-called “consumers” would be consulted during planning and report to the Ministry of Health on annual performance (Ministry of Health 1998 17-24); these “consumers” were not (nor are they now) individuals living in Downtown Eastside Vancouver.

The process of regionalization through the nineties eventually led to the creation of the Vancouver Coastal Health Authority, one of six health regions in British Columbia. The 32 regional and community health boards merged into five geographically determined macro regions (the sixth health region being the Provincial Health Services Authority) under the BC Liberal government’s A New Era for Patient Centred Health Care (BC Ministry of Health 2001). Numerous health care workers discussed with me challenges with adapting medical care to the needs of those in the community who were newly HIV infected and substance using, in the midst of these structural changes within the health care system, as well as an increasingly antagonistic political climate between health service providers and the provincial government, as the BC Liberals swept the 2001 election. Dramatic cuts in public spending to services meant that the wider material determinants of health were left to the wayside.

Their first two years in office saw the provincial government cutting personal and corporate taxes while severely restricting social service expenditures, worsening living conditions for the urban poor.12 Said one physician,

That was the beginning of major [upheaval]...To make matters worse, the Liberal government had just come in, they were axing administrators, so they were all worried about protecting their jobs. The clinic went from a 5 day a week, 9 to 5 hours, to 7 days, 12 hours a day and no one was running the joint.

The physician described experiencing the greatest challenges during “slow times,” such as holiday seasons, when staffing coverage tended to be minimal.13 Institutional dynamics were
shaped by decision making higher up, especially concerning which programs to support (outreach or in-clinic nursing; daily versus weekly home care visits).

A number of providers discussed with me the level of frustration in the community during the formation of the RHAs, saying that clinic staff felt as though they were continually undermined by management. One community physician described the politicking between management and health care staff saying, “They had bought in to the toxicity at a high level...management perceived the new changes as ‘watch out.’ As time went on, it became more and more toxic.” Increasingly, health care providers’ hands were tied as budgets were clawed back at the health authority level; more so with a perceived lack of consultation concerning the work already taking place in the community at a grassroots level. Naming a number of locations where clinical care is coordinated by the health authority, the physician went on to say that the majority of experienced people eventually quit or moved into different (often administrative) roles, to avoid the clinical environment.

When I asked health care staff whether this environment impacted patients, they overwhelmingly said that it did—in some cases they found their clinical judgment was undermined, particularly with respect to more liberal approaches to addictions treatment (e.g. methadone provision), in other cases they felt they were severely restricted when it came to advocating for additional supports for particular patients. Here is another way in which staff-administration relationships impact care provider-patient dynamics: inner city residents are often those individuals who frequently access the health care system but who have little reason to trust individuals in positions of authority—it can be extremely threatening to have substantial staff turnover, losing the few individuals who are trusted, particularly when battles between administration and nurses or physicians restrict capacity for clinical staff to act as advocates for their patients. And for patients who already experience difficulties remaining engaged in the
health care system, because of homelessness, poverty, and ill-treatment due to one’s social position and identity, the vagaries of a bureaucracy may be the proverbial last straw.

III. IMPACTS ON HEALTH

Such micro-political dynamics are not limited to administration-staff conflicts within community clinics—epidemiological and clinical outcome research regarding HIV in the Downtown Eastside was well established by the time the V/RHB transitioned to Vancouver Coastal Health. Many of the individuals involved in research also provide medical, nursing, and ancillary health care services to people living with HIV in the inner city; dissenting views between health care providers related to the appropriateness of research studies, needle exchange programs, and abstinence versus harm reduction ideology, have been widely published as editorials in medical journals, op-eds, and media interviews. For instance, antiretroviral medication in the community is commonly tied to the ingestion of methadone. Suddenly, politics of methadone, substance use, and harm reduction are part of the everyday experience of HIV care.

A major component of challenges in negotiating different personalities within the system relate to differences in the commonly held beliefs and conventional practices concerning addiction, poverty, and mental illness. A substance-using patient does not necessarily know which physician or nurse they will see in a given environment, or a particular attitude this individual will take toward them, e.g., whether their substance use is an illness or a lifestyle choice. This increases what anxiety may already be provoked for some patients as they enter into the medical system. To this day, HIV positive individuals navigate not only the structure of the health care system, but a complicated mélange of personalities and attitudes toward substance use, medical care and research practices, all of which are informed by images and figurations of homelessness, drug use, and sex work.
That said, attitudes and judgments that inform decision-making need not be directed toward drug users or HIV positive individuals themselves to have effects on their experiences within the system. Professional discretion in practice issues may create another point of transmission for stereotypes, tropes, and related views. Disagreements regarding the utility and appropriateness of nutritional supplementation, for instance, divide health care providers into those who refuse to complete supplement forms because the additional support “[will be] going to go to drugs,” and those who believe that “our purpose is to judge whether the form is correct and not to make decisions based on the downstream events.”¹⁵ This is but one example of how bureaucratic elements of health service provider-patient interactions are laced with authority; patients then have to negotiate differences between the various staff they interface with on a daily basis.

The anonymous bureaucracy of health care institutions can exacerbate problems related to judgment calls regarding appropriate support for drug using patients. For example, when VCH changed its policy regarding nutritional supplements (in the form of Ensure, a high-calorie meal replacement/supplement) in 2008, patients were required to re-apply for the supplement, requiring a physician consultation. Those who were approved (or re-approved) were now only able to receive a maximum of 90 days, three cans of Ensure per day, within a one-year period. Previously, Ensure had to be consumed in sight of a staff person, with the labels of the can removed, due to concerns that individuals might sell the can on the street for a couple of dollars. Under the policy changes, one can is to be consumed and the other two given (labels removed) in a brown paper bag, but only for 90 days. The other 275 days of the year, patients fend for themselves.

Whether or not the assumption that any given patient would sell their supplement is reasonable, the actions of an additional consultation and reapplication for supplements, removing the labels off the can, requiring observed ingestion of one can, and limiting the length of time
one might receive a supplement for, all demonstrate the ideological orientation of the medical system: a focus on fiscal accountability and universal rule-making over individual patient needs, presumptions about the ubiquity of patients “hustling” the system, and a view of care providers as gatekeepers to services, rather than patient advocates.

Social policy, health policy included in that, develops within networks of relationships involving various governmental and non-governmental actors, along with their attendant interests, preferences and values (Prince 1996, 241-242). What may seem like a straightforward, necessary, and unquestionable policy issue becomes suffused with power dynamics within its social context—this makes up the context within which action takes place and possibilities for agency are determined. When a policy plays out, those dynamics are enacted and attendant layers of meaning are taken up by those who abide by, as well as enforce, the actions. With both the 2008 Ensure policy and disagreements between providers over nutritional supplementation for drug users, hierarchies that exist within the clinical environment are reinforced and power dynamics re-established, both between patients and care providers, as they determine who ought to receive supplements and additional benefits, as well as between care providers and system administrators, as they disagree about priorities in spending versus patients’ health.

My emphasis on policies and programs is meant to indicate that it would be mistaken to believe that the challenges I’ve described here are all in the heads of the various actors within the system. Additionally, I submit that a number of policies within the community, along with a series of changes with respect to health reform in 1997 and then in 2001, reflect an increasingly neoliberal climate in British Columbia. Neoliberal ideologies are individualist; they undermine various forms of collective action and exacerbate differences amongst rich and poor through the endorsement of the market, while simultaneously diminishing the social institutions that buffer the effects of income inequality on health (Coburn 2000; Coburn 2004). There is a shared
philosophical foundation, between the political context of health care services in British Columbia, models of adherence, and images and figurations of substance users and those who are non-adherent to ART: each rests upon a notion of the self-as-rational-agent and a model of human action as that of rational actors. The underlying ideologies of neoliberalism and neoconservativism within the wider political context of British Columbia operate concurrently with preconceptions and stereotypes of substance use, one set of ideologies and conventions reinforcing the other. Rather than offer rational actors as a model for health decisions, I claim that philosophical suppositions concerning rational agency have a hand in generating conditions under which non-adherence to therapy occurs.

THE POLITICS OF HEALTH IN THE INNER CITY

Focusing on micro-politics within HIV services, turf wars, rumours, and personality clashes runs a risk of representing historical dynamics of HIV care as utterly idiosyncratic. Let me dissuade the reader of that notion by pointing to connections between the locality and particularity of health politics and structural aspects of the health system and wider social processes in health, as laid out in the previous pages. Understanding complexities in HIV care requires an understanding of health care reform and a neoliberal shift within the wider political climate; in particular, this includes the influence of neoliberalism on health and social services and ultimately the social determinants of health. As I will be working toward an account of adherence to ART that is about social identity and agency, my emphasis will be on ways in which a neoliberal orientation is intertwined with conceptualizations of persons receiving care. This will orient the reader to ways in which social identities, conceptions of “the self,” and agency all have a hand in adherence to ART.

Consider again the roles that one’s social identity as a member of a drug using “population” might have within the health system. Negative judgments concerning addiction, for instance, are transmitted through the use of commonplace terms in clinical practice, whether or
not a practitioner has a punitive attitude toward drug use or drug users. When urine screens test positive for drug residue, the urine is “dirty,” while individuals who have not been using are “clean.” Patients refer to being “cut off” of their methadone when a script runs out and they are unable to refill it. Medical language overlaps with popular imagery of addicted individuals as “junkies,” and practices surrounding addictions care, particularly methadone maintenance therapy are imbied with social meanings of addiction and substance use—those of deviance and transgression.

More explicit references to tropes of substance users float through medical literature—along with common references to chaotic and self-destructive “lifestyles,” which reinforce a notion that substance use is simply about choice and morality, some have gone so far as to imagistically juxtapose members of the Downtown Eastside community with those of “polite society.” One article discussing some challenges of medical care in the Downtown Eastside quotes a physician working with the addiction service at St. Paul’s Hospital as saying, “imagine some disheveled injection drug user sitting beside a mother in a waiting room, or a loony screaming, yelling and slamming doors” (CMAJ 1998). Given popular images of drug users, the mentally ill and the homeless as polluting, I submit that this image constructs those living in the inner city “other” in contrast to the normalcy and unstated purity of the mother.

The stereotypical images of drug users and the mentally ill tap into two common themes within neoliberal (and neoconservative) thinking: fears of contaminating a productive population with a set of permanent welfare users; and an idea that beneficiaries of social policy, users of the welfare state, are only those undeserving, marginal poor, rather than mainstream members of the community who receive child tax benefits, public education, and health care services. The women who I followed throughout the project would often be told what the cost of their medications, supplies, hospital stays, and services was to taxpayers—this, in combination with an underlying notion of substance use as transgressive, suffuses these rhetorical statements with
those same notions of desert that are part of the larger ideological framing of health policy within a neoliberal political climate.

There is a particular view of the self that is reinforced by the neoliberal turn in the health reform that took place in British Columbia through the late twentieth century and, as I’ve described, reflected in practice and policy. Neoliberalism posits that economic behaviour can be understood in terms of rationality, individuality and self-interest, and further, that these characteristics account for all social action (Peters 2001; Chopra 2003). At an individual level, this vision of selfhood is reinforced within neoliberal health care reform, as potential patients are compelled to become entrepreneurs of their own health (Osborne 1997, 186), endlessly self-examining and self-governing (Petersen 1997, 194). At a structural level, this is aligned with economic ideologies of the market: decentralization, privatization, deregulation, and a focus on efficiency and accountability. Thomas Osborne describes neoliberalism within health policy and governance as proposing surrogate variables to measure abstract notions of health, “in the form of targets relating to finance, pharmaceuticals, recovery rates, operations, patients, waiting lists and so forth—tending even towards a generalized quantification of the health field” (Osborne 1997, 185). Both individual and structural aspects of neoliberalism are reflected in women’s experiences of HIV care in the inner city of Vancouver.

The expansion of epidemiological surveillance in the community and the compulsory nature of some of those studies for individuals accessing ART can also be understood in this light. We might also consider the use of PARIS to be part of this orientation—the importance of surrogate variables and markers of productivity trumps the need for face time with patients and trust-building in the health care system. Importantly, these issues are not strictly directed toward substance using individuals. As I’ve begun to discuss, very little policy concerning the Downtown Eastside seems to escape reliance on, and reinforcement of, preconceptions of poverty and substance abuse. Signage around all of the community clinics preemptively state
that certain medications will not be prescribed, indicating to those in the community that their place of residence suffices to categorize them as either addicted or perpetually on the brink of relapse. Efficiency and accountability in the Downtown Eastside, within bureaucratic spaces of medical care, relies on the wide application of tropes of addiction, reinforcing a sense that urban poverty is ultimately a source of deviance.

As policies continued to advance through the 1990s and 2000s, services for those living with HIV in the Downtown Eastside have become increasingly interconnected with a large number of governmental and non-profit social service organizations. From the mid 1980’s onward, a push for privatization within the government has led to a greater reliance on partnerships with non-profits, many of which have expanded the scope of their services in response to this movement. Today, the women that I followed interact with the follow programs and organizations, all of which reflect this melding of state and voluntary sectors to varying degrees: Health Authority-operated community health clinics (CHCs), health drop-in centres, needle exchanges and outreach services as well as home care nursing; BC CDC street (outreach) nursing; hospital-run HIV specialist clinics (both for men and women and for women only); non-profit society health clinics; non-profit society housing units that also employ nursing or clinical aide staff as well as other program staff enter to provide health care; day programs providing food, education, and social support for HIV positive individuals; and emergency services for urgent/acute care as well as for outpatient IV antibiotics through a short term care component of the emergency department, also known as “fast track.” Each of these sites of care is also a site where tropes of drug use, urban poverty, transgressive women and neoliberal ideology, embedded within health reform as well as within conceptions of the self, operate.

Although health system restructuring and views of the self that are promoted in both liberal and neoliberal thoughts extend well beyond the Downtown Eastside, there are important differences between health care use in the neighbourhood and the vast majority of communities
in Vancouver: individual health care within the inner city is interrelated to a large number of
other institutions and understood within a public health ideological frame. Housing programs for
residents also provide medication services and the administration of assistance cheques as well
as meals. Clinics run by the Health Authority are designed as “one stop shops” where patients
might be able to receive medical care, counseling, nursing consultations and dental care among
other services, so long as they are able to wait the four to five hours it would take to see each of
those care providers, fill in the various forms and requisitions, and in some cases, file their taxes
to ensure that the clinic is appropriately reimburses for services rendered. Epidemiological
studies, some of which partner with the community non-profits working contracted by the Health
Authority, orient study objectives to effectively rationalize the extensive network of agencies and
services.

For all of the reasons to endorse certain aspects of programs and services—take the one-
stop approach as an exemplar—there are also unintended consequences, many of which are
unable to be measured in outcome evaluations of the services. The issue of measurement and
evaluation is one I’ll examine further on. With that in mind, let me continue: within the inner city
in particular, the lines between public health and individual health care become blurred,
reinforcing ideas of the neighbourhood and its residents as wards of the welfare state in all
aspects of their lives, forming an institutional ghetto of approximately a 10-block radius. These
daily interactions are often justified on presumptions of universal psycho-social instability,
concerns about people “hustling” the system, and notions of incompetence. This, in turn,
influences ways in which people respond to an imperative to follow medical advice. Although I
am cognizant of the possibility that my pointing to some of these consequences has the potential
to create backlash against providing services and support to community agencies (a move I am
not endorsing), refusing to name these issues runs an even greater risk, insofar as ignoring micro-
political issues has a tendency to leave dominant understandings of medical care in the community uninterrupted.

As I have tried to emphasize in the introductory pages, Vancouver’s inner city is treated both in the popular press as well as in medical research as a homogenous zone of iniquity, effectively coralling its inhabitants at the interstices of private and government organizations. Spatial stigma is reinforced discursively through media depictions as well as academic literature, and in practice, through institutions that form its borders. In Downtown Eastside Vancouver, this includes tropes of drug users, the homeless, and the mentally ill as feeding off the public coffers, failing to ingest medicines such that they put the “general public” at risk, and inhabiting an area of land radically divorced from productive society. Clinical practice decisions, such as requirements that individuals link their methadone to ARVs and that all medications are witnessed and dispensed daily, are not isolated from these tropes.

Thus, it is both inaccurate and potentially harmful to interpret health care decision making as though patients, within the inner city and otherwise, operate according to ideals of a maximizing, health-seeking, rational agent who weighs the pro’s and con’s of a given set of choices within restrictions, values, and needs of their individual lives and follows through with medical advice in order returns to a state of optimal (or near optimal) health. I will argue in later chapters that this idealized picture of health care engagement requires an enabling social structure, but that this is not the context in which medical care is experienced for those living in urban poverty. Individuals living outside of the Downtown Eastside are not compelled to interface with numerous (often punitive) arms of the state on a daily basis; imagined features of their social identities do not necessarily provoke discriminatory reactions to the medical needs they articulate; their homes provide a means of escape from the gaze of the systems that administer health and social policy, reinforcing an image of separate public and private realms. No such divide exists within the inner city, save for an individual’s ability to remain elusive, at
which point they are no longer seen as willing to be “engaged” in achieving health and social security, considered deviant in contrast to a health-promoting neoliberal ideal. My analysis of the qualitative fieldwork, interviews, and literature regarding HIV care therefore references back to this context of care, in an effort to understand social action within the health field as being not simply about deviant, transgressive, or incompetent individuals, in need of a paternal hand to guide them.

INTERSECTING STRUCTURES OF THOUGHT

Inner city residents are depicted in contrast to an “ideal” agent, but as I shall argue in this project, this is an impossible ideal to achieve given the context within which HIV/AIDS care occurs. As such, members of the community are ubiquitously portrayed as substance users and the stereotypes related to their cognitive capacity are employed as an *explanans* for their failure to meet a fictional ideal. *Homo economicus* describes the self that is at the heart of this vision of agents: individualistic, unitary, rational, maximizing (Meyers 1997, 2). An increasing focus on the part of epidemiology, toward “life skills,” coping, resilience, and so forth, are reiterations of psychological aspects of health. As discursive tools, these psychological constructs prioritize conceptions of selves that fall in line with an economic perspective of behaviour (a component of neoliberal ideology), which then comes to represent a universal human nature. Those who are unwilling or unable to participate in “care of the self” are deemed deviant, incompetent, and non-compliant with the interests of the medical system. They are subsequently dealt with in ways that further diminish mutual trust between patients and health care providers.

Working from a concept of the self that is demonstrated through medical discourses that pathologize particular “kinds” of people, I shall attempt to articulate a relationship between social identities and non-adherence to ART, using this as an entry point into a critique of concepts of agency and autonomy as they so often employed within bioethics. I examine how biomedical rationales, operating in HIV research and care, endorse a normalizing view of the self
and agency, which shapes possibilities for women’s health-related action. What I take to be a problematic about this vision of the self and the view of agency that follows from it, is a connection to what G.E.M. Anscombe has called a “Cartesian psychology” view of intention: the idea that intention is an interior act of the mind, produced at will, such that an agent herself determines the description under which her action occurs. This is a view that Anscombe criticizes on the grounds that actions are neither private nor interior; I suggest that views of health care decision making within much of medicine makes this sort of mistake. In contrast, conceptualizing the ingestion of medicines and the giving and taking of medical advice as social actions that relate to identity and the processes of meaning making will, I hope, move us away from the Cartesian ghosts that continue to haunt contemporary moral philosophy and away from (mis)understandings of adherence to ART that continues to operate in medical discourse.

The discussion of historical and political contexts of health services in the community has situated problems of adherence to HIV care in such a way that it can now be examined through an alternate lens—namely, what I conceive of as the three intersecting streams of philosophical investigation: (1) epistemological issues regarding how social actions such as the ingestion of medicine (or its reverse, the refusal to participate in regimes of health) are studied and understood, represented by medico-scientific literature (2) the constitution of identity through medical discourses and micro-practices of power in the health care system, and (3) how contours of agency are determined by and through interpersonal and institutional dynamics in medical systems, which are themselves influenced by these discourses along with the politics of health.

*Epistemological issues regarding actions that constitute adherence/non-adherence*

The first set of concerns centre on epistemological issues within studies of women’s access and adherence to ART, which I have begun to problematize in this chapter, and will continue to do so throughout. I connect my field experiences with Ian Hacking’s work describing the effects of interactions between “discourse in the abstract” and “discourse in the
face-to-face.” My aim to expand his analysis of the ways in which concepts, practices, institutions, and people are formed and shaped (Hacking 1999, 127). Hacking writes, “[t]he use of these categories often has real effects upon people. Not necessarily direct effect, related to the mere knowledge that the authorities or experts classify you in a certain way. The effect can be indirect, when the classifications are incorporated into the rules of institutions…” (Hacking 2004, 297). There is room here to develop an understanding of the micro-processes by which agents within institutions are materially constituted, how they are living bodies with certain capacities and abilities and how categorizations influence the scope of certain agents’ possibilities for themselves.

*The constitution of social identity through medical discourses and the micro-processes of power within the health system*

My second mode of investigation picks up from the first. I contend that transgression and pathology are inscribed on particular bodies, in particular locations, through the role that medical discourse has in constructing of social identities. I aim to demonstrate how these inscriptions are historical as well as political, how they are connected to disparities in long-term uptake of ART and embodied as attendant health outcomes. In Chapter Five, for instance, I consider how women’s decisions to leave clinical settings against medical advice are linked to their categorization in that setting as a member of a “kind,” and argue that resultant pathologies must be understood in light of the role that social identity categories have in influencing the quality of negotiations surrounding health care services. This approach sits in contrast to more psychological views of social construction and the self, as well as the tendency (in some philosophical circles) to reduce social constructivism to idealism (Nightingale and Cromby 2002, 703). Indeed, I mean to refute the use of materialist grounds to reject social constructivist theses by my refusal to oppose constructedness and materiality.
The connection between these outcomes on the one hand, and identity, agency, and subject position on the other, invokes a kind of nominalism. HIV positive women who live in Downtown Eastside Vancouver are frequently identified as either female sex workers and/or injection drug users; they are categorized according to risk group affiliations and in the words of Ian Hacking, “come into being by a dialectic between classification and who is classified” (Hacking 2004, 280). In picking up and extending the threads of constructivism, I shall subsequently argue that disparities in outcomes surrounding HIV care are at once contingent and over-determined. I demonstrate how discourses (both practices and texts) are inscribed on particular bodies, often in predictable ways, but pace Hacking, that this need not involve reflective endorsement or affiliation with one’s group identity.

By now it should be apparent that the wider milieu of HIV/AIDS care that I have chosen to investigate is not exhaustive—this is not an attempt to claim a new, dominant explanation of what adherence really is. The alternate explanations and histories I have presented represent my own interests and concerns, as well as some concerns and interests belonging to the individuals who participated in the research I carried out. Likewise, the vignettes, examples and interview excerpts that will be presented throughout the dissertation are not the sum total of life experiences of the participants and should not be taken as such—these are women’s representations of some aspects of their everyday lives, particularly those that are salient to their navigation through complex and sometimes hostile social environments, including the medical system. Importantly, an emphasis on experience and on counter-narrative is not meant to treat the identities of those whose experience is presented as being self-evident; thus, I am not presenting the real stories of the drug user or the homeless woman.

To make this mistake would be tantamount to naturalizing difference and reinforcing a solidified (some might say calcified) view of the self, leaving untouched the questions of how difference is constructed and naturalized (Scott 1991, 777; Vogler 1998, 331). Similarly, with
respect to the utility of narratives for understanding clinical encounters, I am not making the claim that attention to narratives ought to be included in medical practice as part of the repertoire of clinical tools. Not only does an uncritical reliance on narrative experience as a technique of medicine reify a solidified view of the self, it places narrative within the very same reductionist, causal logic that I am arguing against (Frank 1998, 198). What a critical view of narrative can offer, however, is a method that accepts instability and relationality as constitutive elements of identity, employing these qualities in an effort to understand complex social action. This metaphysical take on identity is crucial to appreciating a constructivist thesis.

This is a particularly challenging issue when the analytic moves being made throughout this dissertation are in the domain of academic philosophy—where the intellectual canon, technical jargon, and stylistic elements have a tendency toward elitism and away from colloquialism and everyday experience. Much of the effort in the work is one of translation. I employ different narratives in order to get at various ways in which ideologies, ascribed identities, and dominant narratives influence adherence to HIV care, while trying to maintain some fidelity to the participants’ own views and ideas. In particular, I feel it important to focus on inconsistencies and tensions that operate within the institutions that circumscribe the Downtown Eastside and the interactions within the settings where HIV care is delivered to its residents on a daily basis. These tensions are ones that women themselves must negotiate while accessing care. Contradictions and inconsistencies also reveal cracks and fissures in the logic of dominant narratives offered by conventional adherence research.

*Interpersonal and Institutional Contours of Agency*

The final aspect of the work moves from interactions between practices of medicine and more theoretical and philosophical aspects of it, to the social actions of ingesting medicine, participating in the health system, or alternatively, withdrawing from care. I argue that the subject positions available to HIV positive women, made possible by interlocking systems of
privilege and power and standard depictions of ideal agency, rationalize the active as well as passive refusals to participate in regimes of health. An inability to grasp the relationship between adherence, agency, and ascribed identities within the domain of HIV care (as in conventional approaches to adherence) relates to an illusive yet pervasive “self” of modern Anglo-American philosophy: the unified, transcendent, rational self, which appears to be the seat of autonomy just because of its relationship to a particular body. A critique of this view of the self underlies my analysis of women’s agency within the health care system. Analytically and methodologically, this work pushes against both dominant (masculine) versions of autonomy as well as substantive and/or relational accounts of autonomy that fail to radically revise the concept. With respect to the latter, I have in mind more recent attempts to simply expand the conceptual ground of autonomy to include those who are typically excluded from its scope (e.g. women), without radically revising its ontology.18

I am concerned with one form this conservatism takes in particular. In it, we see an expansion of the considerations that are included in the scope of autonomy, increasing its required conditions. This often results in delineating necessary social conditions for the exercise of autonomous agency, its proponents arguing that were these conditions provided for, individuals typically excluded from being autonomous would achieve this state of being. Those conceived of as “Other” are brought into the fold of liberal humanism.19 To radically displace the liberal humanist standard entails a movement away from a reliance on transcendent universals and toward plurality and provisionality of embodied experience. Understanding experiences and counter-narratives within differentiated, local sites steps away from a vision of a grand, unifying narrative, such as is offered by liberal humanism. What I am attempting to give, then, is an alternate way to conceive of autonomy that sidesteps the problems of difference, along a commensurate methodological approach to its study.
CONCLUDING REMARKS

As I have tried to indicate throughout this chapter, HIV/AIDS in the Downtown Eastside community is part of a crisis that has played out on a daily basis for more than twenty years, with an extensive number of roles for various actors and institutions. Understanding at least some aspects of these roles and their history is necessary for an adequate examination of relationships between categorization and representation of HIV positive women in the inner city, how these categories operate in medical settings, and ways in which medical decision-making is influenced by these processes. Importantly, the content of this chapter has also begun to articulate worries about received views of the self and agency that operate in liberal philosophical traditions. An idealized conception of human agents is taken up within biomedical research and care, including the field of HIV/AIDS; it sits at the heart of dominant narratives concerning the HIV epidemic and non-adherence to ART, as well as mainstream accounts of agency and autonomy. As such, it is my contention that any sincere attempt to grapple with gendered and racialized disparities of HIV care obliges the dismantling of this fiction.
CHAPTER TWO
BIOMEDICINE AND THE CANON OF LIBERAL HUMANISM

There was once a time of caste and class, when tradition decreed that each group had its place, and that some are born to rule while others to serve. Law and social norms defined rights, privileges, and obligations differently for different groups, distinguished by characteristics of sex, race, religion, class or occupation. Social inequality was justified by church and state on the grounds that people have different natures, and some natures are better than others.

Then one day Enlightenment dawned, heralding a revolutionary conception of humanity and society. All people are equal, these upstart men declared, inasmuch as all have a capacity for reason and moral sense. Law and politics should therefore grant to everyone equality of political and civil rights. With these bold ideas the battle lines of modern political struggle were drawn. (Iris M. Young 1987, 536)

Having proposed that a set of shared philosophical premises underpin both the conventional thought concerning non-adherence to antiretroviral therapy and the conceptions of the self and agency that operate within biomedicine, I want now to lay out the central elements of what I will argue to be this common (and ultimately problematic) philosophical ground. Liberal humanism is the canonical basis of moral and political thought within biomedicine; it draws heavily on western intellectual traditions whose unifying logos has arguably been dominant since the Enlightenment (Shildrick 1997, 2-3). As offered above by Iris Marion Young, the Enlightenment narrative places liberal humanism at the crux of the attempts to defeat epistemological and moral dogmatism and undermine social inequality predicated on group-based difference. In contemporary political liberalism, this sentiment is expressed by the goal of anti-perfectionism,¹ seen in the work of individuals such as John Rawls and Charles Larmore. Rawls gives the argument that a political conception must be freestanding—that is, based on principles that govern a wide range of political life and not any one comprehensive doctrine concerning the appropriate ends or conception of the good (Rawls 1993; Larmore 1999). Similarly, Larmore describes liberal thinkers as basing their philosophical commitments on the conclusion that political associations should not attempt to foster any ultimate ends of human existence—the political principles that reasonable citizens can recognize and share, irrespective
of their differences; political principles can thus be expressive of their divergent wills (Larmore 1999, 600). It is for the fear of coercion and the embrace of practices of toleration and pluralism that liberal humanism maintains that a capacity for reason and moral sense is shared by all citizens in virtue of their human nature and that this is the basis upon which moral and political institutions and the actions within them are justified.

In her own work examining various implications of liberal humanism for feminist bioethics, Margrit Shildrick offers what I take to be an uncontroversial definition of the tradition:

By liberal humanism I mean that conception of the moral and social order, dominant since the seventeenth-century Enlightenment, in which gender-neutral, individual and autonomous actors conduct their own lives and enter into contractual relations with other individuals on the basis of free will and rationality. (Shildrick 1997, 5)

The modern understanding of medical practices as a set of secular, technical-rational endeavors in which respect for autonomy and individual rights are fundamental values is indeed contemporary, but its philosophical roots anchor these priorities within the intellectual tradition that Young and Shildrick describe.

The concerns of the past half-century, that medical practices be embedded within a secular, anti-paternalistic, and anti-perfectionist theoretical framework, are not radically distinct from the philosophical lineage of Kant, Mill, Locke, and Hobbes. A brief glance, for example, at what is often called the “principled” approach to bioethics reveals that the principles (respect for autonomy, beneficence, non-maleficence, and justice) are meant to capture significant elements of deontology, consequentialism, and contract theory; all of these see value in the liberal humanist framework. Shildrick argues, for instance, that patient autonomy has taken centre stage in bioethics and progressive liberal humanist theory in this field constructs a model of interaction “in which supposedly gender-neutral individuals meet together, as co-active and putatively equal moral agents, in a relationship mediated by a complex series of rights and duties” (Shildrick 80-81). Despite a diversity of justificatory schemes amongst these different branches of ethical
thought, there is a commitment to suppositions of liberal humanism—hence an emphasis in bioethics on who the decision-maker is and the conditions of consent (ibid). I would add to Shildrick’s analysis that the prominence of the principled approach in bioethics has likewise been related to its ability to function amidst the pluralism that is definitive of contemporary liberal democracies. Accurate or not, medical ethics idealizes clinical interactions in a manner similar to that depicted by Larmore and Rawls—that a physician/health care team not set the ends or conceptions of the good (i.e. quality of life) for patients, but provide evidence and best practice guidelines so that patients are able to choose for themselves and follow a health care plan that fits within their wider set of values, preferences, and ends.

More generally, we might bear in mind that a move toward collaborative forms of medical decision-making and a view of patients as clients and active stakeholders within the medical system, rather than passive recipients of expert care, are also arguably aspects of the intellectual cornucopia of liberal humanism. In this respect, Deborah Lupton describes the orthodox critique of medicalization—that is, a set of issues related to the worry that ever-increasing aspects of life are viewed through the prism of scientific medicine—as being in agreement with liberal ideals. Lupton writes that “the notion that individuals should not have their autonomy constrained by more powerful others is central to the ideals of the medicalisation critique. In concert with liberal humanist ideals, critics argue that becoming ‘medicalised’ denies rational, independent human action…” (Lupton 1997, 96). Although Lupton goes on to problematize certain aspects of the orthodox critique, it nevertheless serves to indicate the importance of liberal humanism in orienting the direction of moral and political thought within contemporary medicine. Thus, influential ‘empowerment’ language and a rise of consumerist jargon can be at least partly understood as responses to the authority and control that professionals had long held over health and well-being (Starkey 2003; Newman and Vidler 2006).
Given that liberal humanism is in many ways the fount of contemporary Anglo-American philosophy of allopathic medicine, it might seem Herculean to suggest that an examination of both premises of the tradition’s canonical thought and its application within a particular field of biomedicine (HIV/AIDS care) will demonstrate why these philosophical foundations need to be radically reconfigured. But such is my project. I propose to outline what I take to be fundamental presuppositions of the tradition, beginning with roles played by universality and a capacity for reason within theories of the self and of agency. Liberal accounts indissolubly link justice with the use of impartial reason, for which universality is a central criterion, (Meyers 1994, 20-21). It is from a combination of universalism and rationality that other identifiable features of liberal humanism—impartiality, equality or sameness, and independence—stem. With respect to sameness, those who carry out moral reasoning are generic individuals in virtue of their universal capacity for impartial reason. Public use of reason is also what moves a person out of what Kant refers to as an immature reliance on others, thereby heralding the value of independence. It is by way of these concepts that a liberal humanist tradition pictures the “self” as rational agent. Agency is therein idealized as autonomous. Even as much as it is accepted that in life, agency and autonomy are not always one and the same thing, a liberal view of agency sets rational autonomous agency as its ideal.

While we can certainly identify a number of significant features embedded within liberal views of agency and the self-as-rational-agent, rationality has an organizing role within the tradition; it is the thread that runs from the Enlightenment through contemporary liberal philosophy. Reason allows the Kantian moral subject to transcend cultural norms and contemplate moral truth; for a different branch of the liberal philosophical tradition, reason allows for coherent ranking of desires and use of instrumental reason to maximize desire satisfaction (Meyers 1997, 2004). This shared foundation is where I begin my discussion, though I focus throughout the project on the forms of liberalism that stem from the latter
Examining the intellectual legacy of the Enlightenment, Lorraine Code describes instrumental rationality as a contemporary instituted imaginary. An imaginary encompasses principles of conduct (norms, customs, expectations, etc.) as well as social structuring of knowledge production, including shared notions of its scope and limits (Code 2006, 30). The instituted imaginary of contemporary western liberal societies emphasizes an ability to know the world as a set of objects available for contemplation, dispassionate investigation, prediction, and control (ibid, 32). This view of an impartial and independent self-as-rational-agent also holds that unification or integration of values, beliefs, and judgments along with a capacity for transparency or self-reflection, are crucial for autonomous agency. These features of agency are components of the interlocking assumptions of a universal and essential human nature endorsed by liberal humanism. Moreover, as I shall attempt to demonstrate, each of them functions within biomedicine.

**THE GHOST IN THE MACHINE: THE RATIONAL SELF AND THE LIBERAL TRADITION**

To start, I propose to examine the role that the concept of the “self” plays within the liberal tradition. Broadly speaking, the “self” is described as pivotal for contemporary philosophy, sitting at the intersection of metaphysics, epistemology and ethics (Meyers 1997, 1). It is no surprise then, that the liberal tradition places the “self” at the centre of moral theorizing. Although certain branches of modern liberalism might recognize the social embeddedness of human agents, or might attempt to approach moral and political theorizing from the perspective of how people in a society ought to be treated (rather than asking what an agent ought to do), liberal ontologies paradigmatically adopt some form of methodological individualism. Social actions, structures, and conditions are to be explained vis-à-vis the properties of their constituent individuals and social goods are aggregations of individual goods (Taylor 2003, 195). The appropriate function of social institutions, including that of medicine, is to facilitate as best as
possible, and in a non-discriminatory way, the life plans of its citizens (ibid, 196). Importantly, these citizens are generic—group differences are transcended such that different religions, skin colours, sexualities and sexed bodies are not supposed to alter individuals’ life options, be it in their formation or execution (Young 1987, 536). The tradition’s emphasis on universal rationality and its focus on the individual agent, attempts to ensure that differences amongst persons and groups are entirely private and accidental.

Of course, these generic selves, as seen by the liberal tradition to exist prior to discourse and to the “social,” do have certain qualities; the most central of these is a capacity for means-end deliberation and instrumental forms of reasoning. As Diana Meyers describes:

The view of the self that has dominated contemporary Anglo-American moral and political philosophy is that of *homo economicus*—the free and rational chooser and actor whose desires are ranked in a coherent order and whose aim is to maximize desire satisfaction…The self is identified with the instrumental rationality of the marketplace. (Meyers 1997, 2)

Rationality is understood to be one of a number of conditions that manifests self-governance. Within this bundle, one might also include other mental capacities such as an ability to comprehend relevant information and freedom from cognitive pathology such as psychosis (Christman 2005, 333). This is importantly connected to understanding and promoting one’s own interests. Liberalism takes it for granted that individuals are the best judges of their own interests. An overwhelming concern, as seen in the emphasis on anti-perfectionism and anti-paternalism, is to ensure that citizens are protected from inappropriate moral and political interference.

Because the capacity for reason across the breadth of liberal accounts is understood as being unrelated to various forms of identity or group-related difference it is the bedrock of liberal equality (Shildrick 1997, 108). Shildrick likens this to the influence of Cartesian dualism within the liberal tradition, as well as the widely shared notion of an essential (and static) human nature (ibid). Likewise, an emphasis on transparency and reflective self-evaluation dovetails with
universalism in such a way that a liberal self-as-rational-agent is ultimately a disembodied self that is capable of acting on reason and operating under constraints of rationality (Searle 2001, 91-95; Kaufman 2005, 449). It is this self and these rationally derived constraints that establish rights and duties, and mediate moral action.

The long-standing distinction between mind and body within the western philosophical canon has also meant that human agency is defined in terms of rational action (Shildrick 1997, 76; Meynell 2009, 2). The preferred account of agency, according to traditional ideals, is of independence, choice, control, rationality and freedom in action (Isaacs 2003, 131-132). And as I have suggested, concepts of agency are deeply indebted to conceptions of the rational faculties of the self—deliberation, volition, identification, and responsiveness to reasons. The understanding of a relationship between autonomous agency and a self endowed with rational capacities is widely shared amongst liberal humanists: an essential feature of human agency is that one’s capacity for action is informed by one’s reflective self-evaluation, free of external control or manipulation so as to ensure that reflective deliberation is indicative of one’s “self.”

Rational self-governance is thought to entail the capacity to comprehend and act on moral reasons (Litton 2007). This includes the ability to discriminate between instances where the consequences of one’s actions are within the scope of one’s evaluative capacities as compared to those that are not, and anticipates that the agent will act accordingly. As such, rationality and responsibility are intimately related to one another within the liberal humanist tradition. In legal philosophy, for example, the notion of a person is one who acts for reasons and is likewise potentially able to be guided by reason, such that they use standards and rules as premises in practical syllogisms to guide their actions (Morse 2000, 253). This view of personhood connects to responsibility in the following way:

The law’s concept of responsibility follows from its view of the person and the nature of law itself...Legally responsible agents are therefore people who have the general capacity to grasp and be guided by good reason in particular legal contexts. They must be capable of rational
practical reasoning. The law presumes that adults are so capable and that the same rules may be applied to all people with this capacity. The law does not presume that all people act for good reason all the time. It is sufficient for responsibility that the agent has the general capacity for rationality, even if the capacity is not exercised on a particular occasion. (Morse 2000, 253)

Even outside of its legal determination, conventional philosophical treatment of responsibility certainly deems rationality and responsiveness to reasons to be significant pre-conditions. A defeating condition of responsibility (and thus agency) consists in something like frank manipulation, but it will not suffice to absolve responsibility by saying that one simply didn’t know better, or one failed to consider predictable downstream effects of one’s actions (MacIntyre 1999, 312). That is, it matters in determinations of responsibility, whether one is indeed capable of practical reasoning and understanding various consequences of their actions. We can infer from the presence of both incentives and disincentives to action, that agents are presumed, by co-citizens and social institutions, to respond to incentives and disincentives on the basis of reason and guide their actions accordingly. Agents are therefore held responsible by others and by legal institutions; at the same time, they are presumed to understand themselves in this way.15

Furthermore, Margaret Lock has suggested that the relationship between rationality and responsibility applies not only to moral or legal responsibility for one’s actions, but to epistemic responsibility as well (Lock 1993). To be held as an epistemically responsible agent is to be identified publicly as one with rational authority. Credibility as a knower is premised on universal standards of rationality, which invoke not only images of carefulness and lack of bias, but a disconnect between the mind and body—that is, the possibility of a detached stance. These serve as the descriptors of responsibility within scientific activity and amongst scientists, which of course includes medicine and medical practitioners. Consider, for example, the designation of physicians as medical “experts.” Having expertise in a particular domain (e.g. cardiovascular medicine) implies a high level of credibility based on knowledge relevant to that domain;
credibility is socially affirmed through practices such as licensing procedures. Historically, medical paternalism has been justified on the grounds of the expertise of physicians as compared to laypersons (Ho 2009, 497-498). This relationship has, of course, become inverted with the increasing significance of patient autonomy in medicine, but the relationship between knowledge, autonomy and responsibility remains. Autonomy has risen alongside health promotion movements, which urge both increased health knowledge and responsibility for health outcomes upon patients themselves. Health care providers are meant to offer relevant information and coordinate (but not direct) care, while patients are to be responsible for their health. The significance of this movement has been its emphasis on agents’ capacities to comprehend health-related information in a way that enables them to be epistemically as well as morally responsible for their health and to recognize their competence in determining what facts, principles, inferences, etc. are necessary for them to make decisions that fit within their conceptions of the good. Health decisions are therefore deferred to those individuals who demonstrate epistemic competence.

The ideals of patient-oriented care are indeed reflective of the broader liberal ideals of anti-paternalism and anti-perfectionism. A case-in-point is the conceptualization of compliance to preventive health recommendations (e.g. immunizations, screening tests). Informed by theories of motivation (Becker and Maiman 1975), compliance to this aspect of health care imports an implicit view of the self-as-rational-agent. On such accounts, persons need (1) basic health knowledge, (2) to understand themselves as vulnerable to a given condition, which is meant to be prevented and (3) to appreciate the condition under question as negative, while understanding (4) that the intervention being presented is effective, but with few difficulties. Such selves are informed, motivated, and self-interested. This view of the self implicitly suggests that rational selves will be motivated to act in a way that enables them to take responsibility for their health—this is the whole premise of the health promotion movement.
Selves that fail on these regards may be self-deceived about the barriers to the action or the severity or likelihood of the condition, but these are “knowledge”-based issues that are taken to be resolvable with input from those with the appropriate expertise. With such knowledge in place, it seems that one would have to be either irrational or irresponsible to not follow through with interventions that are relatively straightforward, effective, and prevent serious harm.

**RATIONAL AGENCY AND THE UNIFICATION OF THE SELF**

As central as a capacity for reason is, any sufficient liberal account of agency must also inquire about the values that an agent holds. It is inadequate to ask only whether she has a cognitive capacity for rationality that is necessary to bring about her ends. On liberal paradigms of agency, individuals are thought to express *themselves* in a deep and significant way, through their reasons for action. Thus the importance of authenticity and authorship of the values, norms, and judgments that an agent might hold and act on is clear. For example, in her neo-Kantian position on the self, Christine Korsgaard argues that by *choosing* which desires to act on, the agent *reveals* herself through that choosing:

> The idea that you choose among your conflicting desires, rather than just waiting to see which one wins, suggests that you have reasons for or against acting on them. And it is these reasons, rather than the desires themselves, which are expressive of your will. The strength of a desire may be counted *by you* as a reason for acting on it; but this is different from *its* simply winning. This means that there is some principle or way of choosing that you regard as expressive of *yourself*, and that provides reasons that regulate your choices among your desires. (Korsgaard 1989, 111; original emphasis)

Korsgaard rejects the idea that her position is indicative of any deep metaphysical commitment to what the “self” is; she suggests instead that the necessity of the unification of desires, judgments, aims, etc. is a practical or pragmatic one. Because one has *reasons* for one’s actions, the deliberative standpoint from which one chooses a course of action *just does* generate a sense of oneself as unified (Korsgaard 1989, 111-112). Korsgaard’s discussion emphasizes a point that is generally shared across the liberal tradition—that an agent expresses herself by her choices and that this expression of the self regulates what subsequent choices might be made.
Individuals are seen as agents insofar as their patterns of being-in-the-world demonstrate a kind of unity of meaning and values within their life and not merely a temporally continuous stream of consciousness (Ehman 1994, 29).\textsuperscript{18} Were some level of unity or stability of values and preferences \textit{not} a necessary feature of the usual picture of rational agency, it would be impossible to discriminate between instances of akrasia (weakness of the will), from an agent’s revision of their particular intentions.\textsuperscript{19}

Korsgaard’s discussion of the relationship between agency and the deliberating, choosing, rational self helps to make sense of the view that rational agents must demonstrate a level of authenticity with respect to their reasons for action. Conventional liberal views of the self portray ideal modes of agency as demanding a certain psychological depth; an agent’s ends are meant to stand in relation to their wider set of beliefs and values.\textsuperscript{20} Making deliberative choices requires that a self identifies with \textit{something} from which to derive reasons for action, which need not exist at the present time (they could be in the past or future); being able to carry out a rational life plan therefore requires that one’s personal identity is continuous over time (Korsgaard 1989, 112-113, my emphasis). With respect to the future, ensuring continuity places importance on the integration of various projects, ends, judgments and values. Newly discovered or developed identity traits must be reconciled with those that had been previously acquired and deemed central.\textsuperscript{21} Identity traits are thought to be made up of beliefs, desires, preferences, values, commitments, ideals, social roles—the sorts of things that are integral to making and executing life-plans (Oshana 2005, 78). \textit{Central} identity traits, “[hold] us in a peculiarly tenacious way” (Oshana 2005, 79); as the seat of the rational will (Frankfurt 1988) it is generally taken to be unthinkable that one would be the same person, should such traits cease to exist altogether. Integrity is bound up with personhood, the whole way down. On various accounts, internal mental capacities hierarchize various desires and integrate these with beliefs, other
desires, interests, etc., in order to maintain a sense of coherence and consistency over time, such that the self is called “unified.”

As mentioned, it is often taken for granted that forming contradictory beliefs or intentions undermines integrity; maintaining a commitment to self-preservation as rational agents entails maintaining the coherence of one’s beliefs, desires and preferences (Buss 2006, 314). This view is most distinctively put forth by Harry Frankfurt in his account of agency as wholeheartedness. Similarly for other philosophers though, contradictory mental states undermine integrity and authenticity, qualities that are understood to be crucial to rational agency and selfhood. To be otherwise would mean a person was “out of their mind” (Meyers 1997, Scheman 1997, Buss, 2006). Similarly, when philosophers talk of an “identity crisis,” they mean to articulate how a lack of integration, or a disagreement between temporal, affective, and psychological aspects of oneself, is problematic for autonomous agency as well as self-continuity.

With respect to the relationship between health behaviour and mainstream liberal accounts of the self that I am currently explicating, we might also say that one’s values or beliefs related to health need to be integrated into the wider set of preferences and commitments if health behaviour is to be sustained within one’s everyday life. Even habitual actions performed for the sake of health presuppose on-going identity (Korsgaard 1989, 112). Serious illness or the onset of disability can prompt the kind of identity crisis that is said to come with a lack of integration, when it is the case that the new way of being, new commitments and new beliefs and values are not continuous with one’s prior sense of oneself. As we saw from the initial discussion of conventional adherence research offered by the introductory pages, persistence in adhering to medical advice and medical care requires that individuals have the ability to integrate new bodily practices (ingesting pills) along with particular beliefs (the pills are important) as well as commitments.
The temporal continuity of the self-as-rational-agent extends to the past as well. Memory has an important role, therefore, in the continuity of the self and processes of unification and integration. Continuity of memory determines whether one is the same person across time, marks one as a bearer of responsibility, maker of promises, and recipient of trust (Scheman 1997, 125). Self-deception, of which modification to memory is surely one aspect, is widely thought to undermine agency, inasmuch as one’s fidelity to one’s endorsements are suspect (Calhoun 1995). Of course, all memories can be said to be subject to change over time. But the relationship between continuity, memory, and marks of rational agency are precisely the grounds for claims that individuals with inconsistent memories or wide ranging discrepancies between their significant central traits and personal memories are not persons of integrity and are suspect when it comes to determinations of rational autonomous agency.

The profundity of this issue is seen with philosophical accounts of psychological trauma, which is taken to be a paradigm case of the undoing of continuity and integration of the self (and commonly examined as a risk factor within the HIV/AIDS literature). The experience of trauma, defined as helplessness in the face of the perception that one’s life is seriously threatened, is thought to amount to the denial of personhood, generating a sense that one’s subjectivity is useless and worthless. The subsequent re-living of erratic and powerful memories distorts one’s sense of self—as well as intrusive and uncontrollable memories, physiological responses such as hypervigilence, and involuntary psychological effects that include the sense of a foreshortened future, are experienced as an undoing of oneself (Brison 1999; Brison 2002). One’s pre-traumatic life must be reconciled with one’s post-traumatic life, in order to carry on. Such experiences also reinforce the notion that agency demands rational control of all aspects of the self, given that a lack of control with respect to mental states, affect, and bodily experiences due to trauma is pathological.
The significance of psychological trauma for health behaviours is an issue I return to at a later point. For now, let me leave the reader with its import for conventional views of the self, in liberal philosophy and medicine—trauma, as a form of pathology, indicates that untraumatized selves (healthy selves) have a much more seamless integration of memories, beliefs, identity traits, etc. over time, and are, for the most part, also in control of their affective responses. Trauma therefore offers insight into how liberal humanist ideals of the self function within biomedical discourse: it is those selves who are rational, integrated, and unencumbered by bodily presence that are free of pathology. Trauma also points us to another tenet of liberal philosophy, which is of interest to those working in social medicine and social determinants of health: most liberal accounts carve out a place for social supports for autonomy, which include things such as protection from violence/trauma and the promotion of rights to bodily integrity, along with other substantive external supports. Insofar as negative liberty within liberal philosophy recognizes and attempts to protect the individual from becoming “undone” by others, the positive aspects of liberty are also recognized by most accounts.28

SELF-REFLECTION AND TRANSPARENCY AS CONDITIONS OF AGENCY

Integration (unification) is important for establishing the authenticity of traits that are central to the rational self, but this is not the only feature that works alongside rationality within conventional liberal accounts. First, there is the process of integration itself: if one is to be integrated, one must be able to contemplate and understand what sorts of things are supposed to be brought to bear upon one another, such that potentially conflicting aspects of the self are modified and/or rejected. Moreover, most views also hold that there must also be an understanding of how the agent has come to possess the norms and ideals that guide her conception of the good. It will not be sufficient to say that a set of values are well-integrated or unified, if it is the case that they have been adopted without adequate reflection. Consciousness about one’s self is therefore held as being a critical aspect of the rational grounding of agency.
Repressed desires and unconscious drives might make for interesting personalities, but they do not, on conventional accounts, make for particularly rational ones.

Self-examination and self-scrutiny, for better or worse, make the flux of one’s inner experience known to oneself; self-reflection solidifies one’s sense of who one is. As an example, Frankfurt’s account of personhood argues that self-identity develops through the aspects of one’s character that, upon examination, one cannot help but accept or reject (Frankfurt 1988; 1999). As the example of self-deception alluded to, the integration of what an agent cares deeply about requires reflection on what she finds to be meaningful. Reflexivity, on Frankfurt’s view, is an indispensible condition for purposeful behaviour of all kinds. Even amongst those who do not hold a structural view of the will, in which first-order volitions (e.g. what one wants, intends, etc.) are reflected on and assented to through second-order desires (e.g. desires to accept or reject one’s first-order volitions), the ability to self-critique and self-reflect is paramount for autonomous agency.

Meyers suggests that this view is symptomatic of the modern infatuation with the trope of the self-made man, a trope that is a part of the instituted imaginary of western liberal democracies. Even within accounts that admit that selves are raised in particular societies and cultures, one can at least approximate the ideal of creating oneself from scratch by rationally defining oneself (Meyers 2005, 43). Now one need not hold one’s self conception in stark relief at all times—but inasmuch as traits, values, affects, etc., are to be integrated and rationally endorsed, a level of transparency and self-reflection is necessary for autonomous agency and is an indicator of rational selfhood. Without reflective endorsement, there is no way to ensure authenticity or authorship of the traits, desires, beliefs, values, and preferences that make up a person’s conception of the good and sense of themselves.

In health behaviour literature, rationality and self-reflection are conjoined in a particularly important way. With respect to health, good citizenship, and good statecraft have
transformed the notion of health from a right of citizenship to a duty; as I have begun to describe, the move away from paternalism in medicine, along with the rise of health promotion and health education, emphasize the importance of providing health-related information so that citizens are able to make reasoned decisions about their health and in so doing, take responsibility for it. Implicitly then, ill health, disease and disability are personalized failings (Osborne 1997). What is of further significance is that the ideals of reflexive self-fashioning function in a parallel and mutually reinforcing way with those of rationality in the neo-liberal health agenda—the rational, entrepreneurial individual, endowed with reflexive capacity, participates in self-examination, self-care and self-improvement, moderating the burdens of individual health on society. Within health literature, cognitive life skills such as self-efficacy have increasing prominence as mediators of good health (Petersen 1997, 194-196). The healthy agent is the rational, self-monitoring, self-governing, responsible one.

**LIBERALISM AND THE RATIONAL ACTOR MODEL OF HEALTH BEHAVIOUR**

Each of the features I have outlined, rationality, unification/integration, self-reflection/transparency, are captured by Diana Meyers in her description of the “unitary” self:

The *unitary self* is the independent, self-monitoring, self-controlling self that has been pivotal to autonomy theory. As the seat of rationality and thus rational deliberation and choice, the self-as-unitary is often viewed as the ground for free will and responsibility. Indeed, the self-as-unitary and the autonomous self are so closely identified that they almost seem indistinguishable. To be rationally reflective and free to carry out one’s rationally reached decisions is to be autonomous, on many accounts. (Meyers 2005, 29)

Here, then, is the normative view of the self that I am arguing operates within much of biomedical practice and ethics. This is the view of the self that I discussed in relation to the concerns of biomedical ethics (consent, decision-making capacity) and, as I will describe below, this “self” is presupposed by approaches to health care decision-making that view individuals as rational, instrumental reasoners. Rationality is the keystone of this view, generating the necessity of the processes of integration, unification, and self-reflective evaluation.
Contemporary liberal accounts like those offered by Korsgaard and Frankfurt link identity and autonomy through rationality (Herman 2002, 264). It is from a view of the self-as-rational-agent that the substantive features of autonomy are set. Meyers’ description draws attention to the intimate connection between the self-as-rational-agent and autonomous agency within the ideal picture. Under “normal” conditions, agents reflectively endorse desires, preferences, beliefs and wider ends, which are generally reconcilable with one another. From these, they rationally choose their courses of action, utilizing what is seen to be a universal capacity for practical reason in carrying out actions that will enable them to achieve the majority of their ends, or at least a maximally satisfying combination of them.

The importance that the normative ideal places on the relationship between rationality, unification, and reflective deliberation can be discerned through the trope of the wanton, as can the implications of deviating from this ideal. A wanton is an individual who does not care about the desires or motives that generate action, thereby failing to achieve the ideals of rational autonomous agency in one of a variety of ways:

This is a disparate group. What unites them is their failure to form and attempt to realize volitions of a higher order. This failure may be due to any of the following: cognitive naivete, inability to reason, inability or reluctance to engage in critical self-reflection, immaturity, preponderance for instinctual behaviour, preponderance for addictions, acute weakness of the will, indifference, and even laziness. (Oshana 1998, 262).

Marina Oshana explains that those individuals whose wantonness can be taken as a mark of non-agency are disqualified from agency on the grounds of epistemic failure (e.g. extreme youth, hypnosis, psychosis); physical or psychological compulsions to act (i.e. not being in control of oneself); and in certain instances, problematic social/historical life conditions that prevent one from formulating higher-order volitions (Oshana 1998, 269-273). The price of wantonness is high: being an author of one’s actions requires the evaluative command of reflective reason and this is the condition of being a person (Herman 2002, 264). A wanton fails to meet this
condition, deviating from normative standards set by the liberal ideals of self and agency and therefore needing of paternalist intervention.

It is noteworthy that these failures are the same characteristics that determine whether an individual is competent to make health-related decisions and to consent to medical procedures. Typically, those within the health care system who do not live up to the normative standard are children, individuals with dementia or acute mental illness, and in times not so distantly past, women. Just as the wanton is seen as a non-agent, these individuals are not looked upon favorably as agents capable of informed consent or shared decision-making on the grounds that they do not achieve the conditions set by the accepted view of rational autonomous agency. Oshana’s discussion can be used, in this case, to demonstrate the convergence between the features of the liberal humanist self, the common understanding that egregious social/historical conditions can undermine agency, and the use of the idealized conception of the self within medical practice and medical ethics.

THE LIBERAL HUMANIST SELF IN PRACTICE

It is imperative for the aims of my project that we appreciate how liberal normative ideals are also apparent within behaviouralist approaches to health decision-making, including conventional analyses of adherence to ART. Research and analysis of adherence has been strongly influenced by health behaviour models, developed outside of the domain of antiretroviral therapy, such as the Health Belief Model, Social-Cognitive Theory, Theory of Reasoned Action, Theory of Planned Behavior, and Protective Motivation Theory (Simoni et al., 2008; Munro et al., 2007). These accounts follow a rational actor model, which emphasize the necessity and significance of adequate and reliable information in order for agents to carry out actions. Such models also presume that agents have a relatively stable set of priorities and preferences. Preferences may be modified by additional propositional knowledge, but like liberal accounts that posit a lack of stability as a mark of wantonness, it is a type of failure of
autonomous agency if health-related preferences are not present and stable to some degree. Moreover, a rational actor model also presumes that deliberative processes will be undertaken so as to attain the greatest possible preference set amongst the stable, ordered preferences and priorities.  

A number of features of health behaviour theories are shared with liberal conceptions of the self-as-rational-agent and rational autonomous agency, which are worth dissecting. In both, agents have certain desires (e.g. to be asymptomatic) and beliefs about how to achieve them. They go about discharging those through actions such as following through on medical advice, taking pills, etc. These health behaviours are understood to be the result of means-end deliberation, which motivates the action to be carried out. In their consideration of how it is that some patients manage to be treatment successes, Alfonso and Toy suggest that, “patients who take the time to reflect, consider their situation, and make conscious choices are more likely to maintain adherence” (Alfonso and Toy, 2007). Being “ready, willing and able” to commit to medications requires behaviour change: one must move from being pre-contemplative about their behaviour to being able to think about making changes, resolve any ambivalence, prepare to undertake action, and then follow through with initiating action. By referring to those who are adherent as “committed” to treatment, responsibility is invoked.

Just as in the need for reflective deliberation on a liberal account, sustaining behaviour change requires self-monitoring of new behaviour. Even analyses of adherence that attempt to include factors such as perceived social support often share these features of behaviour change theory (Simoni et al., 2008). Thus, pill-taking seems to implicitly follow a model of rational autonomous action, whereby a patient reasons and follows through on consciously endorsed decisions as an expression of the integration of their core beliefs and desires, making them thereby responsible for those decisions. Mind over matter.
One appeal of a rational actor model may be that it seems to explain why it is unsurprising that drug users are predictably non-adherent. On this view, non-adherence is a kind of failure of rational agency and drug users are seen as not achieving standards set by the liberal view of the self-as-rational-agent. Four elements of rational actor models are at work in generating what seems to be a widespread view of why it is that drug users are non-adherent to ART:

Readiness to Engage: Drug use is taken to be a paradigmatic indicator that patients are not ready to engage with ART, and for that reason, are non-adherent when they do make such attempts. Various interventions are designed specifically to enhance the ability to make such individuals rationally motivated to be involved in treatment: coaching and motivational interviewing regarding drug consumption, methadone substitution therapy, a rational intervention designed to reduce opiate cravings, and failing those, directly observed therapy, particularly in locations where other incentives (e.g. meals) are provided.

Persistence and Preference ordering: Part and parcel with the idea that drug users lack motivation to initiate behaviour change is a concern regarding their ability to maintain that behaviour. The need for preference ordering is thought to be part of persistence—one must be able to prioritize certain actions over others, if health behaviour is to be sustained within one’s everyday life. To the extent that drug use is seen as interfering with health behaviours, it is presumed that drug users do not prioritize their health over their use of drugs, leading to non-adherence. What priority drug users do place on health care is understood to be minimal or made irrelevant by their inability to follow through on their preferences due to drug use. The lack of follow-through and fickleness may also be depicted as their being “difficult” or acting in a childish manner, a reiteration of their failure of achieving rational agency.

Confidence: Confidence may be both self-directed (as in the case of self-efficacy) or other-directed, for instance when a patient does not trust the authority of the medical system, or that health care providers’ advice just is the rational thing to do. The notion of trust as a form of confidence is particularly significant, as situations of epistemic complexity require that one trust those who are experts in the appropriate field. Drug-using individuals are seen as not trusting the medical system and as not having enough self-confidence (in the literature, construed as self-esteem as well as self-efficacy) to carry through on the decision to undertake therapy. Failures on both of these poles of confidence may be construed as another type of agentic failure, as it is widely presumed that the drug users’ lack of confidence is misplaced (as in trust) or indicative of personal pathology (as in lack of self-efficacy).

Knowledge: Those who are non-adherent may fail in acquiring adequate knowledge, concerning either the benefits of ART, appropriate dosing or common side effects, or knowledge related to the harms of drug use, given that drug use is seen as the prime cause of non-adherence to therapy. Medical advice is construed as rational and its practitioners...
as experts; drug users are often depicted, in the popular imagination, as irrational and lacking knowledge.

In light of an understanding of non-adherence to ART as modes of non-agency, the health care system offers what seem to be rationally constructed correctives to these failures. For instance, it is common to have drug users enroll in directly observed therapy programs and to link ARVs to methadone substitution therapy, as well as offer motivational interventions and coaching around side-effect management within clinical encounters. And yet, drug users continue to be non-adherent to therapy, according to conventional adherence research. The juxtaposition of ongoing drug use with rational autonomous agency and the self-as-rational actor is offered as a part of the explanatory framework of research that attempts to predict and intervene on non-adherence. As I shall show through my own analysis of non-adherence to ART, this juxtaposition is commonly encountered by drug-using patients within the health care system and functions to reinforce negative images and pejorative stereotypes—figurations that make their way into health care encounters, affecting the quality of relationships within the medical system.

CRACKS IN THE FOUNDATION

Oppressed groups find that rationality, intelligence, correct speech, proper body comportment, and the like, reflect the experience and way of life of the dominant white middle class men. Because women or Blacks, for example, often have not been socialized in the same way as those white middle class men, they are less able to conform to these allegedly neutral standards of competence. (Iris M. Young 1987, 538)

The liberal humanist conception of the self—a universal, generic, rational self, entitled (at least potentially) to respect by virtue of the capacity for self-determination—seems like it is the kind of self that we might want to endorse. Regardless of class or caste, one’s capacity for reason is intact until proven otherwise, and even then, there might not necessarily be grounds to interfere with how they choose to get around in the world. If indeed this prevents important overstepping by those with greater access to social forms of coercion, control, or power (agents of the state, physicians, etc.), why might we be concerned with the liberal humanist
underpinnings of biomedicine or, for that matter, with the relationship between this intellectual tradition and conventional approaches to conceptualizing adherence to ART?

There is a cacophony of dissenters to liberal humanism, who hail from a number of philosophical positions; their reasons for dissent are many and varied. The positions can be narrowed down for my own purposes, which are: first, to critique conventional approaches to understanding adherence on the grounds that the methods of analysis that invoke ideals of liberal humanism fail to capture significant dimensions of the phenomena that make up non-adherence; and second, to articulate how ideals of the liberal tradition serve to replicate conditions of exclusion and marginality that they purport to fight. Such conditions are likely to generate the very circumstances that surround non-adherence. To that end, non-adherence is something of a test case for these deeper philosophical worries about the liberal tradition.

The fundamental issue, as it relates to my analysis, is that ideals of liberal humanism attempt to expand the centre of privilege to include members of historically disadvantaged groups, while leaving untouched the normative conceptions of the self-as-rational-agent and autonomous agency. The features that constitute a rational agent—instrumental reason, unification and integration, self-reflection and transparency—are still taken as neutral and objectively desirable standards. But as Iris Young writes in the quotation above, the supposedly neutral standards of liberalism are not neutral, individuals are not generic, and its reason is not universal. As I examine in more detail in chapters Five and Six, the liberal standards reflect the perspectives of those who hold dominant social positions and who quite often occupy a favoured subject position within a good/bad opposition that dichotomizes the norm against those marked as different (Young 1987, 544).36 Thus supposedly neutral ideals may be experienced as oppressive for those who sit on the “wrong” side of the dichotomy.37

In many ways, this critique is at the heart of the concerns launched by feminists who reject the idea that the centre of liberal privilege can simply be expanded. The instituted
imaginary of the autonomous man acts as a *regulative* fiction whose dictates are an impossible imperative for those whose experiences do not model his own (Code 2000, 196; my emphasis); ideals of autonomous agency are impossible for the very same people whose interests were supposed to be protected by the appeal to impartiality, equality, and universal reason. Moreover, as Lorraine Code and Naomi Scheman discuss in their respective critiques of conventional liberal approaches to autonomy, the autonomous man is himself dependent on favorable patterns of social interaction and compliant social structures that often remain invisible contributors to his own attainment of autonomy (Code 2000; Scheman 1997). Thus as a normative standard, the liberal ideals can be argued to be doubly pernicious, disadvantaging certain others while strengthening the centre of privilege for some. Through my empirical research, I attempt to demonstrate how these issues are not relegated to the domain of theoretical and abstract argumentation—they operate within domains of HIV/AIDS research and treatment. The ideals of liberalism underpin a whole set of structures within the health care system that are meant to ensure adequate care, but that assign categories that define certain identities as transgressive and deviant, while the demands of participating in the system make the path to HIV/AIDS treatment quite narrow and challenging for those same people.

Additionally, my critique focuses on problematizing the supposed impartiality of knowledge claims that come from a universal and generic knower. Here is the way that I intend to call into question various assumptions and premises that underpin conventional methodologies of adherence research: because rationality is understood within post-Enlightenment thought to be common and universal, there is no special need to attend to the particularities of individuals’ social locations (Code 2006, 3). This lack of situatedness and particularity reveals that the epistemology (and model of language) given by the liberal tradition is predominantly monological. What is rational for one is rational for any other, thus it is possible to conceive of
a generic and impartial knowing subject who investigates a knowable object, in what can be described as an “I-it” (as opposed to “I-Thou”) relationship.

We see this monological mode of reasoning within the common form that post-Enlightenment epistemology takes. The “S-knows-that-\(p\)” rubric of propositional knowledge attempts to construct the world in terms of atomistic and innocent facts that are observationally verifiable by generic knowers whose social positions are irrelevant to the knowledge produced (Code 2006, 98). But if the universal is itself suspect for representing a position of privilege as a neutral ideal, then methodologies that invoke universality, objectivity, and impartiality must be interrogated as components of the instituted imaginary of contemporary liberal humanism. The interrogation and potential problematization of methodologies is necessary insofar as this imaginary and its components can be argued to hold in place unjust distributions of privilege while perpetuating the rhetoric of neutral scientific knowledge production (Code 2006, 31). An interrogation need not entail rejecting all forms of scientific enquiry—anti-positivism does not amount to anti-intellectualism. In the case of understanding adherence to ART, empirical research is important. It must be subject to scrutiny, though, for the potential to endorse the elements of the liberal tradition that are not as neutral as they appear.

Alternate methodologies may be required, if the knowledge produced by a monological model turns out to be inadequate. A dialogical approach, for instance, might rectify some of the shortcomings of methodologies steeped within the liberal tradition. A dialogical model (“I-Thou”) that emphasizes intersubjective elements of epistemology and language, specifically recognizing the particularity, locality and embeddedness of all claims to knowledge, might be argued to do such a thing. This approach recognizes the limits of knowledge production and the influence of material, social, historical and imaginative structures on what is known.

The issues broached have been brief and are likely to have raised more questions in the minds of readers than answers and no doubt those readers of liberal humanist persuasion have
ready replies to the problems I have begun to point to. Let me assure the reader that over the course of this work the problems with liberal humanism will be clarified, as will the alternate accounts and approaches that I intend to provide. What I hope has been made apparent are the presumptions of liberal accounts: that the self is a unitary, rational, transparent self, who integrates its desires and judgments and reflects on those when acting; and whose actions, by having been chosen on the basis of self-reflective reasoning, are expressive of the will. Agency, within the liberal tradition, is ideally construed as autonomous and rational. These two sets of concepts provide the normative structure of morality, politics and epistemology. It is these conceptions that I have begun to argue are the intellectual foundations of biomedicine, including the conventional approaches to adherence to ART. As my analysis carries on, I hope that it will become clear how these conceptions are flawed, in theory and in practice.
CHAPTER THREE
STUDYING SUBJECTIVITY, INSTITUTING IDENTITY

“We have learned very little that is new about the disease, but much that is old about ourselves.” (Frederick Tilney, 1916)

The problems of how to conceptualize and investigate access and adherence to antiretroviral therapy in Vancouver’s Downtown Eastside are related to a deeper set of concerns I have begun to articulate, regarding the liberal humanist concept of “the self” that operates within medical research, medical care, and public health practices in the domain of HIV/AIDS. Specifically, I have interrogated the intellectual tradition that has inculcated the prevailing norms of rationality, self-mastery, and autonomy within affluent western societies. I turn now to deepen my critique, placing these norms within the scholarly and professional study of adherence to antiretrovirals. I intend to show that there is a convergence between the ontological presuppositions of post-Enlightenment liberalist thought and the behaviouralist orientation of HIV/AIDS research, which is also evident within clinical practice. My claim will ultimately be that the commitments of liberal humanism represent the “self” and agency in overly rationalist and objectivist terms; in the domains of health and medicine, this view of the self and agency fails to capture important and complex aspects of social action.

The production of knowledge regarding adherence to antiretrovirals predominantly employs population-based research. With the current focus on “evidence-based practice,” both clinical care guidelines and health policy are increasingly informed by this type of statistically-oriented analysis. Meanwhile, time pressures and the demand that clinicians consider numerous problems at once (e.g. for multiple patients, issues of diagnostics, outcome expectancies and futility, as well as health system constraints on practice decisions) mobilize the use of epidemiological and demographic data in clinical care. In light of these trends, the chapter begins with a review and critique of the activities that are undertaken within epidemiological
studies that generate data concerning the ability of drug-using women living in Vancouver’s inner city to adhere to antiretroviral therapy.

After considering a number of limitations to statistically driven research methodologies, I move toward a discussion of how objectivist methodologies represent women as a homogenous population, endowed with particular immutable qualities. I argue that the risk categories employed in research and clinical practices call upon and reinforce the idea that women substance users constitute a kind of person. I explore how epidemiological classifications of risk groups (particularly the classification, “injection drug user,” or IDU) can simultaneously function as a rationalization of stereotyping, which has a tendency to perpetuate “application error,” the inappropriate application of epidemiological data to every individual in the group (Grieger 2001, 1700), and impose of a “law of truth” upon individuals, by way of an immutable identity (Foucault 1982, 781). The ascription of identity is particularly problematic when it is tied to normalizing conceptions within society, which exclude non-ideal others from centres of privilege. I have started to give a theoretical argument to this effect and now turn to its instantiation in empirical practices.

Ultimately, I argue that an adequate account of adherence must not only address the multiple dimensions of adhering to medical advice—it must remain attentive to the potential for even its most well-intentioned research efforts to contribute to processes of exclusion and marginalization. At the chapter’s conclusion, I turn to a discussion of qualitative research methodology, arguing that an emphasis on lived experience and critical interpretive practices will yield a far more robust analysis of adherence and potentially avoid the pitfalls that I am suggesting are problematic for population-based research practices, particularly social epidemiology.
RISKY MEASURES, DEVIANT BODIES AND PATHOLOGICAL SPACES

Population-based statistics have played an important role within health system planning and program development, notably because of their utility in identifying social variations in disease incidence, including temporal and geographic patterns in HIV infection. With respect to HIV/AIDS, the impact of social environments on health is also frequently examined in terms of treatment uptake. By focusing on factors that influence the health of populations, epidemiology provides a foundation for public health and preventive medicine practices. Alan Peterson explains the relationship between epidemiological risk analysis and health services, saying, “epidemiology has become so central to the public health endeavor of identifying, reducing exposure to, or eliminating ‘risks’ that it has become almost synonymous with the public health enterprise itself” (Peterson 1997, 197). Risk analysis relating to HIV/AIDS treatment barriers extends this relationship to the individual patient’s bedside. Social epidemiology, a subfield of analytic epidemiology, examines the relationships between broadly defined socio-behavioural and socioeconomic factors and poor health and is an important source of data for surveillance and public health interventions in the Downtown Eastside.

Although the dynamics of smoking crack cocaine have become increasingly topical to HIV research in Vancouver’s inner city, epidemiological surveys relating HIV/AIDS to illicit drug consumption in the neighbourhood have tended to focus on injection drugs and injection drug users (IDU). As previously described, adherence-specific data stem primarily from the BC Centre For Excellence Drug Treatment Program (DTP) database; the database is linked to large cohort studies such as the VIDUS cohort, which provide data concerning demographics, housing, illicit drug consumption, food security, and so on. In the former, drug use survey items function to separate out IDU from non-IDU and stratifies risks related to non-adherence, morbidity, and mortality according to whether a respondent has ever used injection drugs. The latter, made up only of injection drug users, expects respondents to quantify their drug use patterns at six
monthly intervals. For both, regardless of the temporal variations of drug use, “any” injection drug use in the previous time interval (usually six months) or “ever” having injected drugs will be enough to generate an IDU classification.

In order to produce this information, numerous technologies and practices are mobilized. The discursive construction of injection drug users (dichotomized into demographic categories such as male/female, Aboriginal/non-Aboriginal, female sex worker/non-female sex worker) requires that there are systematic ways to provide questionnaires to people who inject drugs, locate and determine whether people are engaged in street level sex work, collect blood samples to establish serostatus and determine viral load, and measure prescription re-fill rates, turning all of these into data. The exposure/risk categories (IDU, FSW) are also found written in individual medical charts, nursing notes and discussed verbally between various health care providers, outreach staff and social workers. Such survey categories are therefore relevant to a much wider audience than merely the researchers constructing surveys, carrying out interviews, analyzing data, and publishing results—researchers who are in fact different individuals at each level of data management.¹

Arguing that the reductionist ontology of epidemiological practices prevents epidemiologists from exploring the full value of a given data set, Philippe Bourgois suggests that conventions of epidemiology tend to result in the neglect of the richest data, by failing to engage with specific variations in responses to what are often culturally loaded questions on survey instruments. Writes Bourgois:

> As soon as the epidemiological data is published in a reputable peer-review public health journal the field no longer seems to care about how the numbers were collected…
>
> The context or atmosphere of the interview site, the phrasing of the questions, the rapport and social network access of the outreach workers who recruit respondents, or the demographics and identity politics of the interviewers remains a big black box. (Bourgois 2002, 261)
There are a number of implications worth mining from Bourgois’ insights, which specifically apply to the epidemiological studies I brought forth in the introductory pages of this work. It is certainly the case that a reductionist, positivist world-view is revealed in the sorts of studies I have been referencing. For example, it is not thought to matter to the analysis of the data that different individuals work on it at each level of creation, collection and statistical manipulation. If “data” just do exist as potential objects of knowledge, to be manipulated and utilized for predictive and intervention purposes, the logic of this division of labour, along with the use of multivariate control to examine statistical significance, holds. But the further implication of this worldview is this: there is no reason to question whether it is ethically or epistemologically problematic to categorize individuals into clear risk groups, or even to treat a particular set of people as a population. A number of challenges can be made to the presumption that the mobilization of epidemiological classifications benignly carves up the world at its joints. My concerns with the procedures that classify drug users are directed toward both epidemiological research practices themselves and the use of the categories generated by this research in clinical settings.

I. CHALLENGES WITH RESEARCH MEASURES

After having followed a number of women in the community as well as worked with their health care providers in community clinics, the application of drug use categorizations seemed to me to be strikingly crude. Within conventional epidemiological methods, distinct drug use practices and reasons for consumption have a way of becoming blended together with the usage of survey instruments; it is no surprise that respondents are then understood to make up one large, homogeneous group. Aside from the challenges of actually remembering how many times one injected in the past six months, qualitative differences within the group “IDU” are passed over by quantitative scales, obscuring what might make for interesting or provocative associations. During interviews and informal conversations, for example, women would discuss
with me their drug use in terms of very personal “triggering” times—anniversaries of births and
deaths as well as typical hallmark holidays like Christmas—these were times when women
talked about feeling most alone, feeling vulnerable or in need of something to help cope, or
sometimes wanting to celebrate an occasion. If the category is based on injection as an action,
women who inject drugs move in and out of the IDU category at tempos that are not often picked
up by surveys. Differences in the meaning of the action are also left out of this quantitative
picture.

Categorization is even more profoundly crude for women who no longer inject drugs, but
who have in the past. Classifying them with those who currently inject (as the DTP data set
does) misses the important differences in life experiences, health situations, and reasons for
engagement or non-engagement with health care that exist between what were already imprecise
groups. Of course, quantitative researchers would argue that if the statistical association is there,
it doesn’t really matter that the categorization is crude or temporality isn’t being investigated.
But this fails to engage with the limits of the data sets and ultimately reinforces the presumptions
and “common sense” that went into survey design and classification systems in the first place—
presumptions that I will later argue are based on cultural images and schemas.

Even for those grouped as IDU who do indeed inject drugs frequently, such that the
survey intervals are appropriate for quantifying their drug use, there is further imprecision and
lack of detail with respect to the a priori variables of interest that are thought to relate to the IDU
category. “Unstable housing,” for example, is determined by whether an individual answers
“yes” to living in a single-room occupancy (SRO) hotel, transitional living (e.g. shelter), or
homeless. As with drug use variables of interest, survey questions inquiring about living
arrangements, incarcerations, etc. are administered every six months and ask about housing or
incarceration experiences in the intervening time between surveys (see for instance, Kerr et al.
2004). Here, the proxy measures of “structural” barriers fail to capture relevant distinctions and
similarities across the institutions that people interact with, while obscuring the fact that it was
the researchers’ own interpretation of what constitutes a structural barrier or what constitutes
“stable housing” that generated the variables.

To illustrate this point further: while the privately owned SRO hotel system is notoriously
corrupted by drug dealing, illegal sub-letting, and crumbling infrastructures, the more desirable
housing units run by various community organizations in the neighbourhood are described by
numerous residents to be laden with byzantine regulations and interpersonal conflicts, such that
even supported/social housing can be relatively unstable. Personality conflicts and personal
experiences in these sorts of housing units are rarely investigated through survey data, even if an
individual respondent raises the subject during survey administration. What type of housing
constitutes stable versus unstable housing has already been determined a priori by researchers
and applied across the spectrum of respondents, regardless of their individual experiences. The
challenges I am raising here are two-fold: there is a concern about how the boundaries of
categories (e.g. IDU) are defined, as well as a concern about the definitions of the correlative
variables that are employed versus those that are left out.

In addition to these challenges, relationships within the health care system are often
either restricted to data that can be examined from the drug treatment program database—the
number of years a physician has prescribed antiretrovirals (i.e. “physician experience”)—or
based on a five-point Likert scale rating the quality of the relationship with a primary care
physician. Again, serious limitations exist with respect to these measures: the kind of data
(number of years prescribing ARVs, individuals’ six-monthly subjective assessment of
relationship quality) cannot access how relationships are negotiated by particular individuals on
a daily basis or how “in the relationship between carer and cared-for, there is a continual tension
on the part of the cared-for between wanting and appreciating care and resenting it” (Fox, 1995).
There is no way to assess the relationships that people might have to a wider institution and how
that might be revealed in their interactions with its representatives.

There is little concern in the epidemiological literature regarding the crudeness of categorizations or the lack of precision in the associations made between them and other outcomes of interest. Numerous individuals within the community are not injection drug users, even individuals who do use other drugs, but they become grouped in as part of this risk category. When the whole of the Downtown Eastside is conceived of in the literature as the IDU epicenter, injection practices and sources of HIV infection shape the space within which HIV care takes place, such that barriers to service use and non-adherence to regimens are ordered and understood (to varying degrees) by practitioners, researchers, and patients in those terms. This affects how individuals from the community are understood by people (say, nurses and physicians) whom they interact with and how they are treated within their everyday lives—the same kinds of events that researchers then attempt to capture in a scale asking about whether people are treated poorly in health care settings. Thus the challenge I have raised regarding the crude nature of groupings within epidemiological research concerning HIV-infected women in the community is interrelated with another challenge, which I articulate below: the pervasiveness of the categories such as IDU and their presumed objectivity, mobilize a series of events that shape possibilities for what actions might arise within health care settings; these actions are then measured as independent events that often confirm the application of the category itself, reinforcing the populist notion of a drug user as a kind of person.

II. CHALLENGES IN RELATION TO CLINICAL PRACTICE

HIV in the Downtown Eastside has been characterized through epidemiological literature as an epidemic of injection drug use. Those who reside in the neighbourhood and are infected with HIV are widely presumed within clinical practice to have acquired the infection through this route of transmission. Missy is an Aboriginal woman in her mid-twenties who grew up in the interior of British Columbia with her mother and step-father; over the years she has lived in both
urban and rural settings, on and off reserve. She and I spent a substantial amount of time together, talking at length about her desire to rebuild her relationship with her family and children and her struggles with drug use and with serious illness. Missy would regularly be assigned the category “IVDU” while in hospital even though she has never injected heroin and continues not to do so. She prefers to smoke heroin, calling needles “dirty.” Upon noting this error on the medical chart to a member of her clinical team, the team member said to me that people in hospital do “just make assumptions” sometimes. While this could be written off as a relatively unique instance of application error, I hesitate to endorse this explanation. Based on my own experience, I am inclined to suggest that Missy was easily (mis)categorized in clinical environments as an IDU because she is living with HIV in the Downtown Eastside, smokes both heroin and crack cocaine, and presents to the emergency department with characteristic infections of the drug-using community (cellulitis, pneumonia, and so on). The trinity of characteristics of Downtown Eastside residence, HIV infection, and any substance use places her squarely in the “IDU” box. In both HIV/AIDS research and clinical settings, this trinity is taken simultaneously as confirmation of categorization and a proxy measure of non-adherence. Because she also has a “reputation” for non-adherence and leaving hospital against medical advice (AMA), as well as a clinical history of drug-related illness, the categorization is further established as apt, even though she doesn’t carry out the specific action that the name of the category refers to.

Missy found herself labeled as an injection drug user when presenting herself to clinical staff by virtue of having a “DTES” address listed as one’s place of residence; the categorization was unquestioned, likely because the designation was in conjunction with frequent trips to the smoking balcony and other bodily practices that are taken to indicate on-going drug use. But for Missy, this was simply not the case. Similarly, Carly’s experience offers a way to see how the supposed stability and conceptual clarity of the IDU category is a falsity. Carly only
infrequently used while I knew her and had also had a relatively long clean stretch a few years
prior to that; regardless of whether she was using at any given time, she was seen by health care
providers (some of whom were also involved with research that she had participated in) as a drug
user. When I first got to know Carly, I would often find her out on the hospital’s fourth floor
balcony, where the smoking pit was. People would buy, sell and use drugs there. But people
would also catch up on comings and goings of the Downtown Eastside neighbourhood—gossip
and rumours being a valued source of information about the latest busts and potential work
(primarily drug dealing but also under the table construction and odd jobs)—they would call on
old favours, trade cigarettes for candy, magazines for slippers, visit with one another and get
away from the ward dynamics. Hospital staff would inform one another about patients’ presumed
drug use by saying “she’s been out on the fourth floor an awful lot.” The IDU classification was
invoked whenever Carly left the observed spaces of the hospital, which she strongly protested.
She would prefer in these instances to have me accompany her when leaving the ward to get a
newspaper or some cigarettes, as it gave a veneer of legitimacy to her activities.

It also need not be the case that a historical record of group membership (accurate or not)
be in place—as discussed above, being a woman living in the community is nearly enough for
the presumption of participation in sex work to get off the ground. The fact that a substantial
minority of women who work in the sex trade do inject drugs (Shannon et al. 2005b) means that
the practice of injection is imagistically connected to sex work; evidence for one is often taken as
evidence for the other due to the statistical regularity of the conjunction of the two. If, as a
number of epidemiological studies assert, place is a proxy for risk behavior, one need not
actually be an injection drug user to be categorized according to risks attributed to injection drug
use in the community. In light of the relationship between the community and drug use, a
number of women who regularly use the women-only evening services of a community clinic in
the neighbourhood would make sure that I knew they were not drug users or sex workers—they
were older women, impoverished on disability or limited pension plans—protesting the identification of themselves as drug users reinforced to my mind that there was a general association between drug use and living in the community.

I have argued that research practices that follow an objectivist epistemology import a sense of the stability of its categories, which carry over to clinical settings. This might be more appropriately viewed as a mutually reinforcing relationship, as various individualizing characteristics and traits, generated within clinical settings are taken up and employed in the research literature as well. In a recent review of barriers and facilitators for HIV treatment among injection drug users, the authors write, “In addition to the instability resulting from compulsive drug-seeking behaviours, challenges also stem from the fact that IDUs often exhibit several characteristics, such as homelessness and psychiatric illness, which severely complicate the challenges of HAART delivery…” (Wood et al. 2008). While its use in epidemiological research refers to individuals’ acquisition and use of illicit substances, the term “drug-seeking” is a psychiatric construct that medical personnel frequently bandy when referring to reports of pain by current (and sometimes distantly former) drug users—reports of pain that often go unheeded or are met with skepticism and negative judgments. The attitudes that individuals with substance use issues meet in the emergency room are not distinct from the language employed within medical research.

The production of knowledge regarding drug use, HIV/AIDS and adherence shapes how people within the relevant categories are conceived of: like “drug-seeking,” the psychiatric language of “instability” and “compulsive,” which are employed in epidemiological discourse, hail drug users as decidedly irrational, if not incompetent. “Compulsive” is particularly significant, as it suggests that drug use is entirely about physiological and psychological craving, rather than a wide ranging set of practices that are connected to illicit and informal economies within the inner city, often the only economies which impoverished individuals have access to.
Likewise, it is only *illicit* drugs that are taken to be sought out compulsively—methadone, presumably, is not taken “compulsively,” as it is a legal substitution therapy. Here again, the historical and structural aspects are left entirely out of the discussion and categorization proceeds to mark an individual as a member of a group defined by deviant actions and psychopathology. This, in turn, shapes the sorts of data that can then be generated by researchers who design the surveys that inquire about psycho-social stability, mood, and cognitive challenges related to adherence.

**IMMUTABLE IDENTITIES AND KINDS OF PEOPLE**

The use of research categories in clinical settings and medical constructs in research practices serves to mobilize a larger set of ideas in both domains. This includes negative stereotypes and cultural images of drug use, which are directed especially toward those whose categories are taken to be indicative of a *kind* of person. A kind, in the very general philosophical sense, consists of a group of objects with some sort of common essence or unifying cluster of properties that define the group. There is an overlap with what may also be referred to as a *type*, a group for which the unifying feature(s) *need not* be essential properties. Both types and kinds are non-arbitrary, but the unity of a type can be contingent or conditional, whereas a kind is generally taken to represent a group with a shared essential properties (Haslanger 2005, 24-25, 31). In arguing that women who are classified as IDU are treated as a *kind*, I am arguing that they are treated as though their membership in the group displays or is indicative of one or a number of properties that are not merely contingent, even though it is the case that the grouping is based on convention and historically mutable facts. A set of social practices that centre on drug injection unifies the group categorized as “IDU.” And certainly, the content of the grouping is determined by convention (as in what constitutes a “drug,” which one would then inject). I take it to be uncontroversial, for instance, that diabetics who inject insulin are not taken as IDU.
Although it may be tempting to say that the IDU category picks out an objective type in the world, when we consider descriptions of IDU within HIV-related literature and the mobilization of the category in clinical practice, it should be apparent that the IDU grouping indeed functions as a kind. The group IDU is united in the literature I have been specifically examining by way of residential neighbourhood and also by key descriptors of their so-called lifestyle, which is presumed to be common. Research related to addiction and HIV/AIDS also emphasizes the influence of certain early life experiences on drug use and risk of HIV infection and psychological constructs such as self-efficacy. More generally, the sensitivity of dopamine receptors in particular areas of the brain are hypothesized to relate to predisposition to addictive substances and behaviours, while recovery literature depicts addicts as perpetually addicted and having to contend with their addictive nature each day, one day at a time. Even though it is not the authors’ intentions, the effect of the multiple cohort studies is to caricature those who use drugs as afflicted with psychopathologies and fatalistically determined to expose themselves to HIV infection through compulsive needle use as well as likely to fail on treatment regimens for lack of motivation, self-esteem, and cognitive capacity. The IDU grouping is more than simply non-arbitrary—all of the features I have listed above effectively naturalize the IDU category and functions to represent drug users a kind of person.

In a 1983 essay entitled, “Making up People,” Ian Hacking begins what is the start of an interesting and productive examination of how certain “kinds” of people emerge hand-in-hand with the categories that are meant to represent or classify them. Hacking describes a “kind” as a way of being or, alternately, a condition of personhood (Hacking 1986, 225). Constructed entities, writes Hacking, are intertwined and interactive; classification and classes emerge mutually and simultaneously in a process that he describes in his early work as dynamic nominalism and later as “looping effects” (Hacking 1986, 228; Hacking 1999). Institutional practices and policies, media depictions, scientific literature, etc., contribute to the identification
of certain kinds of people; their grouping not a matter of carving the world along natural lines, but of societal impositions on ways of being in the world. People who are of a particular kind are products of certain institutions, languages and practices—these set conditions that various experiences of self might take (Hacking 1999, 28). Thinking of Hacking’s thesis in light of the discussion thus far, we might say that the categorization of women in terms of HIV-related risk groups occurs in texts, for instance through epidemiological literature previously examined, as well as through face-to-face encounters within the health care system (amongst other institutions).

In a more concrete explication of this thesis, Hacking gives the example of “women refugees” in order to examine how a set of conditions can shape the social identities of a certain individuals, who then understand themselves as members of a class and subsequently shape the content of the classification. An idea of women refugees as a kind of person is constructed through social events in their home countries, through legislation, lawyers, activists in other nations, as well as through historical understandings of asylum seekers, and so on (Hacking 1999, 10). Being a member of an identifiable kind means one is subject to statistical analysis as well as international policies based on the category and able to mobilize politically around that identity; these actions further inscribe identities upon those who can be classified as such, adding to the content of what is possible for their life experience and altering the lens through which those experiences will be understood. Women refugees come into being, as a kind, as actions associated with classification structure a range of possible ways for them to interact with others as well as how they might conceive of themselves. At the same time, those who are classified cause the boundaries of the classification schema to be re-drawn. It is through various institutions that develop and employ the categories and the content of social exchanges that this mutually reinforcing process takes place.
But in thinking about this with respect to the studies and practices of HIV/AIDS in Vancouver’s inner city, Hacking’s thesis does not contend with all that is going on. Hacking rightly identifies that both text and encounter shape the process of category-making, but by focusing on the ways in which group members (among other individuals) see themselves in the group designation, Hacking relies to a great degree on the reflexive and cognitive aspects of classification. In some examples Hacking does consider the way in which particular bodies are part of the process of classification, for example, in thinking about the construction of mental illness. There is a presumption on his part, nevertheless, that bodies of group members are simply given—shaped by constructive systems of discipline that are taken up by individuals themselves. I contend, however, that the treatment of women drug users as “kinds” of people need not be based so strongly on a self-reflexive process, or be contingent on personal identification and uptake of the categorization, along with its subsequent impact upon a docile body (though this sometimes is the case). Instead, it is possible for the overlapping discourses of research and clinical medicine to interrelate categorizations with figurations, schemas, and other culturally laden modes of interpretation, thereby structuring expectations and actions within settings that will generate further “data” about those who make up the kind.

Hacking does not seem to consider, for example, how the adoption of a social identity might be strategic, rather than an outright endorsement. Although her actions don’t actually match the IDU categorization, I found it significant that Missy would nevertheless refer to herself at certain times as “just a junkie” and also identify herself as a “fiend,” invoking images of the IDU category in something of a misnomer. Significantly, there were times in which these self-designations were strategic—a way to rationalize and minimize her actions that could be construed as non-compliant. Telling me, “I’m such a fiend,” when she had asked me to meet her for an appointment and then remained in the alley to deal as the appointment time came and went, she was indicating that giving me “the run-around” (her words) shouldn’t be taken as a
personal slight. At other times, “just a junkie” was invoked sarcastically as a form of protest, albeit one that is “safe.” Employing terms that enable sarcasm but allow others to minimize the protest are a way to negotiate the “regimes of silence” that are part of women’s lives in the community.

Of course we could say that even the “merely strategic” use of a category does the same kind of work Hacking has reflective endorsement do in his discussion of looping effects. But there is another way in which kind-making need not be self-reflexive. Consider my discussion of the conflation of the neighbourhood with injection drug use—this reinforces schemas or images of drug users as kinds who can be characterized according to geographical location. Likewise, when the majority of data concerning adherence to ART within the Downtown Eastside is based on a small number of research cohorts primarily examining injection drug users, the neighbourhood is linked to drug use patterns in such a way that its residents are imagined to be a clearly delineated and coherent population. This is reinforced by epidemiological surveillance literature in which transmission patterns homogenize each community: individuals from the Downtown Eastside are grouped geographically and contrasted with other Vancouver neighbourhoods having a high prevalence of HIV positive individuals.

In addition to the literature described above, a substantial body of epidemiological literature takes the “chaotic lifestyles of many IDUs” (Kerr et al., 2004) as given, reinforcing what Robertson and Culhane identify as the familiar depictions of urban poverty, drug addiction, and prostitution (Robertson and Culhane, 2005). The comparative and differentiating process is thereby egged onward, without any one individual having claimed IDU status. The caricatures of drug users contrast their characters against idealized individuals whose characters manifest elements of hyper-individualism, norms of rationality, cognitive competence, as well as moral character and responsibility. These elements can be thought of as schemas—mental constructs that function much like a script would—behaviours, actions, and events are interpreted in light of
them, and where explanations are ambiguous or incomplete, they supply missing information. Importantly, they are characteristically intersubjective in terms of content (Valian 1998, 104-106; cited in Haslanger 2008). This means that there might be shared content of the schema in general, even if its particular application is contested. Schemas of drug users help to make up various categorizations used in clinical practice and research; they thereby influence the possible trajectories that clinical practices take; this content can be shared without being endorsed by the person the schema is applied to.⁷

Importantly, the ontology of epidemiological methods treats classifications such as IDU as metaphysically objective—commonalities between members of the group IDU has to do with the practices of group members (injections of illicit substances) and not their relationship to those doing the grouping. Because schemas are themselves part of an intersubjective ontology, the veneer of objectivism serves to diminish recognition of the function that schemas play within its empirical methods. The more widely held a belief, the stronger its potential influence in shaping patterns of thought, behaviour and the material aspects of social life. The move between categorizing and making as a kind of person depends to a great degree on implicit or tacit understandings of the group and applications of those to individuals, such that they become characteristics or traits, rather than mere descriptions. In a scientistic sleight of hand, tacit understandings are attached to seemingly objective facts of the matter and researchers and research practices are removed from the equation.

For those who do inject drugs or who have done so in the past (even for those who are presumed to have done so at some point) being identified as a drug user by survey data and in clinical practice functions to establish an immutable identity. Missy’s story of being mistakenly identified as an IDU highlights how it is through various images and criteria within public discourse that identities can be ascribed to a given individual, such that individuals are recognized or understood to be a member of a particular group, even if the category is not
entirely fitting (Appiah 2005, 66-67). And as Missy’s experience also demonstrated, there is a mutually reinforcing quality between schemas of drug users (irrational, immoral) and depictions of individuals as non-adherent to medical advice. Often, a determination of whether one classification is apt is bolstered by presumptions of the other. Individual IDU are taken as exemplars of a paradigm and inconsistencies (such as Missy’s) are ignored or chalked up to “noise” in the data set. As a researcher, I saw the trinity of HIV infection, neighbourhood, and any drug use, function to inform how people were conceived of and interacted with at other times, when I joined medical students and residents in their rounds, and as a medical student myself.

By way of setting expectations for behaviour and action, particular ways of being are attached to individuals who are taken to be members of the group represented by the schema, which then mobilize other forms of interaction (Haslanger 2006). When this is combined with academic and medical practices that are taken to be descriptive enterprises, a “kind” emerges, whether or not a particular person sees him or herself as a member of the kind. The significant issue here is that schematic conceptual frameworks are part of classification processes; schemas have implications for lived experience, which may then be eventually picked up in subsequent surveys examining HIV treatment experiences or as illness and injury classified by hospital codes that are utilized in morbidity studies of HIV-infected patients. The role of a particular schema, because of the clear distinction between subject-object in objectivist methodologies, obscures this interaction between categorization and kind-making.

Contra Hacking, Sally Haslanger makes a similar point in her analysis of object construction, arguing that it is often useful to understand the effects of classifications that aren’t used to frame one’s intentions or self-understanding:

…it is also important to note how social matrices have an important impact on groups of individuals without the group being an explicit or articulated category and without the members of the group internalizing the narrative and the norms associated with it. In other
words, we need a way of thinking about “object construction” or better, the formation of social kinds, that acknowledges the causal impact of classification, but also gives due weight to the unintended and unconceptualized impact of practices. (Haslanger 2003, 315)

Women who are living with HIV and using drugs are in certain ways an articulated group—the epidemiological literature alone makes that clear. But is it not clear that they have a “group identity” as the term is generally used in philosophy; nor is it the case that every individual who is ascribed “group” membership fits the classificatory criteria, as Missy and Carly’s experiences suggest. Typically, group membership is thought to relate to identification of oneself with the group or label; Haslanger highlights how this need not be the case in order to engender the effects of classification. Hacking’s emphasis on classification determining “conceptual schemes” or thinkable ways of being (Hacking 2004, 284) therefore leaves something further to be explored.⁸

Not all of the women I talked with ascribed to themselves membership in the group “substance user,” but nearly all did feel they were treated in particular ways based on presumption of that identity based on physical characteristics and actions within clinical spaces. This had particular salience when it came to their credibility as authorities concerning their health and well being, and also their respective abilities to adhere to ART. Some (but not all) expressed ways in which their Aboriginal heritage influenced how others saw them, treating them with suspicion and disbelief based on a set of racialized bodily characteristics. Appreciating these issues, I want to argue in the chapters that follow that in order to understand what it means for the classification of women substance users to emerge hand in hand with women substance users as a class, we cannot employ a view of construction that merely or only considers the reflexive effects of discourse. The influence of wider social-historical imaginaries in determining experience need not require that individuals personally identify with criteria of group membership, or self-ascribe to the particular kind. Likewise, a wider milieu within which kinds are mobilized may see identities adopted strategically or as forms of protest.
Methodologically, understanding these complex interactions requires tools of interpretation and knowledge construction that are intersubjective and attuned to the ways in which categories, kinds, and identities may be lived, without being articulated or endorsed.

**CHALLENGES TO THE STANDARD MEASURES: INTERSUBJECTIVITY, MEANINGS AND DYNAMIC TENSIONS**

The concept of a reflexive I, a mindful self independent of the body and nature at large, is essential to the ‘view from nowhere’ characteristic of a post-enlightenment approach to knowledge. Comparative research on the cultural construction of concepts of mind, body, self and emotions has contributed to the questioning of the autonomous, rational, disembodied self as a gold standard for successful personhood… (Lock 1993, 138)

Like liberal humanist approaches to moral thought, fixated on the self-as-rational-agent, a wealth of behaviouralist study constituting a substantial body of HIV/AIDS research is underscored by methodological individualism, a doctrine that can be traced back to Weber’s understanding of social action and social scientific explanation. On this accounting of action, any understanding of social phenomena is seen to rely on behaviour that is connected to intentional states, or, behaviour that has “meaningful” subjective content (Weber, translated 1978, 7). Connecting action to “ideal types,” Weber writes:

> When we adopt the kind of scientific procedure which involves the construction of types, we can investigate and make fully comprehensible all those irrational, affectively determined, patterns of meaning which influence action, by representing them as ‘deviations’ from a pure type of the action as it would be if it proceeded in a rationally purposive way…Only then does it become possible to give a causal explanation of the deviations from this course in terms of irrational factors. (Weber, translated 1978, 9)

The ideal model of human action that is paradigmatically connected to methodological individualism is that of rational action and ideal social agents as rational actors. In Chapter Two, I emphasized that rational actor models endorse normative views of the self that emphasize a capacity for free, rational, desire-maximizing choice, as well as the requisite cognitive capacities (a capacity for self-reflection, transparency of motivations). With this in mind, the philosophical foundation that is shared between liberal humanism and conventional adherence research methodologies can be made clear. As the citation from Margaret Lock suggests, this view of the
self conjoins ethical and epistemological thought: the possibility of objectivity and a detached stance justifies expectations that rational, universal moral standards can be adhered to by any reasonable person and be employed to underwrite standards of responsibility. These “transcendental pretensions” are the foundation of health care ethics (Shildrick 1997, 63).

While it need not be linked, necessarily, to an individualist bias, methodological individualism within the statistical analyses I’ve discussed are so linked, through the emphasis on lifestyle choice and risk, as well as through the neoliberal health agenda that situates contemporary health research, policy, and practice. And although I don’t deny that one’s mental life, living arrangements, and the effects of on-going substance use play a role in antiretroviral adherence, I do want to suggest that an emphasis on individual cognitive components of adherence and proxy measures of “structure” detach acts of ingesting medicines from meanings attached to the acts, as well as from relationships within the health care system, to say nothing of much broader political and economic forces.

A number of recent research publications have attempted to address this, by considering the “risk environment” of HIV infection and barriers to health services. In some cases, previous cohort study data that had generated individualistic risk data has simply been mined for variables meant to be indicative of the wider setting. In other instances community-level data are examined as variables for infection or non-adherence risk. In either scenario, many of these articles have done little to move the discussion of non-adherence and access to care outside of a reductionist, biomedical paradigm or to alter the construction of the Downtown Eastside community as homogenously pathological. The environmental level reinforces a notion of the community and its immediate institutional boundaries (e.g. local policing practices) as sources of pathology and fails to examine large-scale contributors and processes such as the ideologies of neoliberalism within health discourse.
Moreover, analyses of health behaviour emphasize cognitive and motivational aspects of action, constructing these as existing within the subjective set of the knowable object of study. In social epidemiology, pill-taking or following through on medical advice are phenomena within the set of interests and beliefs of individuals patients. They must be, in order to have individual respondents answer survey items that generate data related to the phenomena, which can then be associated with demographic characteristics, drug use frequency, and other categories that can be turned into binary data. This approach to knowledge production posits action as collections of brute data, reconstructing social reality solely in terms of categorical principles (the definitions attached to particular actions) and meanings associated with behaviour for the agent being studied (Taylor, 192). In these studies, social reality is constituted by brute data and is the object of the actor’s subjective beliefs and attitudes. As Charles Taylor argues, this picture leaves out the way in which any meanings other than subjective meanings are part of social reality. Namely, it leaves out intersubjective meanings that are related to social practices and various ways in which social spaces are configured by such meanings. This includes roles that research(ers) play in reinforcing schemas of drug users and constructing the inner city community as made up entirely of a certain kind of person.

Intersubjective meanings are norms and beliefs implicit in institutions and practices at a societal level—they may be expressed through language describing such institutions and practices, but are part of the background conditions (including historical relationships within systems of thought) that allow structures and actions to take place. Intersubjective understandings of autonomy and of contracting, for instance, are part of what constitute practices of negotiation; this includes a certain vision of the agent and her relation to others and society (Taylor, 195). Thinking about negotiation as a form of political behaviour, it would be mistaken to presume it is possible to capture this behaviour through so-called brute data (such as: raising a hand to vote; breaking off negotiations; one’s subjective attitude toward the issue or other parties
involved). The concepts related to bargaining are part the implicit language of negotiation and are held at a societal level; more important to Taylor’s point, the concepts are constitutive of the social reality that one is proposing to investigate as brute data. It is therefore a misclassification of the meanings and constructs involved, to investigate as though they were merely meanings for the individual actors themselves.

These same considerations apply to actions such as utilizing health care, ingesting medicines and adhering to medical advice. Meanings of “adherence,” and what constitutes it are partly constituted by shared presumptions such as the idea that following medical advice is rational and will produce predictable, beneficial outcomes. The concept of adherence is therefore part of the fabric of a society that gives honorific epistemological status to representative professionals of white, western scientific and medical research, particularly when the knowledge produced is thought to allow a high level of mastery over the unruly “natural” (and social) world. But because it is then possible to measure and conceive of associations between certain conditions and the likelihood of non-adherent behavior, certain individuals who are not adherent are classified as such, mobilizing a series of other investigations, actions, programs, interventions, etc., which shape the future possible social reality, all centered around this particular kind of person. Concepts are constitutive of society and of individuals.

Merely adding a litany of “structural” barriers (in terms of housing shortages, SRO hotel challenges, and interfacing with the correctional system) to the cognitive challenges of adhering to medication, without engaging in methodologies that move away from individual behaviour and causal explanations, does little to examine multifarious ways in which different institutions are interconnected, how they must simultaneously be negotiated, the inconsistencies and contradictions in daily life, or the influence of norms and ideologies on social action. An epistemological approach that is devoid of social and historical framing and intersubjective methodologies is unable to examine the contradictions and tensions that are in place within even
the most “successful” programs. As I will examine in later chapters, linking methadone to ART may be successful for some individuals, as may interdisciplinary daily witnessed ingestion programs. But these programs may also reproduce conditions of institutional control and surveillance, which subsequently shape responses to the programs, sometimes for the same individuals who also appreciate being able to partake in them. Such complicated responses and outcomes are not going to be found on standard survey-based program evaluations, nor are they likely to be articulated in one-time interview-administered questionnaire settings. Or if they are, data often conflict and are likely to be “cleaned” up by researchers at a later point in the analysis process.

The underlying methodological individualism of a substantial body of HIV and adherence literature and a failure to engage with tensions and contradictions of the “data” sets are problematic on two fronts: epistemologically, insofar as adherence remains to be adequately understood; and ethically, insofar as quantitative data that individualizes and totalizes the populations represented has a hand in establishing the boundaries and content of the groupings it purports to describe. Quantitative survey data lacks a level of richness, temporality, and particularity that I argue in later chapters must be contended with, if a more complete and complex understanding of women’s experiences with HIV care and adherence to antiretroviral therapy is to be gained. Furthermore, my earlier discussion suggests there is reason to suppose that methods that fail to examine how responses on surveys might be more variable and contradictory than they seem ultimately reproduce cultural schemas of drug users and end up rationalizing the treatment of women drug users as a kind of person.

Insofar as medical care and research are related to self-making and identity, the issue of intersubjective understanding is paramount, as are relationships between various agents within the systems and institutions that are connected to HIV care. Asking, “how do you feel about taking your pills?” on a survey misses a critical component of adhering to treatment, which can
only be recaptured when adherence is understood as a complex social phenomenon. An agent may well have subjective attitudes related to their actions, but they do not themselves create the beliefs and norms that help constitute the matrix of practices in question—the notion, for instance, that illnesses associated with drug use and sexual activity are representative of personal moral failings, such that engaging in treatment and health care relationships for such illnesses would function as reminders of that same such issue. This level of meaning is held within a society and suffuses relationships structuring actions such as pill-taking. This sort of meaning may not be immediate or transparent to the individual whose illness is understood in such ways.

Events, states of affairs, actions—these have meaning in relation to a larger shared field of understanding. The shared field of what constitutes rational action, as an example, is left out of the picture when meaning attached to pill-taking is taken only as subjective, as in the case of reductionist ontologies that treat action as brute level data. Or, shared understandings, for example, of rationality, are included but left unstated and therefore out of the scope of critical debate. Moreover, there is no way to consider the relationship held by the interaction between knower and object of knowledge as contributing to the generation of data; this contribution may be in the form of meanings that are unspoken, but shared, as well as meanings that are presumed to be shared but in fact are not. We lose track of the function that intersubjective meanings play within research practices when we take for granted that the terms of investigation (e.g. adherence to medical advice) have the same meaning in the minds of researchers, as they do for those whose practices are being tracked. When social reality is taken to be brute-data identifiable, one result is an inability to understand certain kinds of problems (current and future) that are tied to the meanings that constitute practices that make up social reality.

The second concern that my discussion of epidemiology has raised is that the methodology attaches actions and outcomes to individuals (or “kinds” of individuals), rather than to modes of social relations. This may be ethically problematic when it is the case that studies
ultimately service the existing schemas of drug users—schemas that depict drug users as incapable of achieving the ideals of rational agency. Epidemiological analysis, along with tendencies to situate data within discussions of threats to the “public’s” health and hospital expenditures, construct those living with HIV/AIDS who are not receiving care against a fictional populace of ideal agents—who do not use drugs or incur health care costs. This ideal rests on a pervasive fiction in the contemporary western societies: that agents are rational, have a unified sense of self, and are able and willing to critically reflect on motivations and life plans. These ideal agents integrate their larger life plan with day-to-day actions; they are responsible and accountable to other members of the moral community. Women who predictably face barriers to continuity of HIV care are depicted as lacking reasoning capacity, reluctant to engage in critical self-reflection, indifferent, and sometimes lazy. Emphasizing mental components of non-adherence accentuates views of substance users as transgressing a normative ideal.

The following chapters address this concern more substantively. For now, it will suffice to suggest that an objectivist stance within biomedical research obscures different ways in which schemas and tropes that are part of kind-making (thus part of the constitution of reality) are not mere descriptions. This reinforces an “ideal” subject and moral community—communities made up of those who are self-governing, responsible and who strive for “health.” This ideal, acting as a relational term, sets in contrast those who paradigmatically transgress the norms of rational agency, leaving unquestioned historical, socio-economic, and political conditions that naturalize this binary. In contrast, my own examination of adherence to ART focuses on historical, political, and socio-economic elements, understood through intersubjective meanings.

A WAY FORWARD: UNDERSTANDING, INTERPRETATION AND CRITIQUE

By suggesting that I might give a different analysis of non-adherence and barriers to HIV care, I am offering a critique of the methodology and research findings of the access/adherence literature, in the Marxian sense of the word “critique.” This is not only a discussion of the
epistemological validity of the research under question; critique, in the sense that I employ it, “trains the weapons of reason at socio-historical reality and sets itself the task of bringing to light hidden forms of domination and exploitation which shape it, so as to reveal by contrast the alternatives they thwart and exclude” (Wacquant, 2004). This critique has been set up by my initial epistemological concerns regarding the limits of methodological individualism in capturing various aspects of barriers to HIV care and non-adherence to ART, but as I have pointed out, it is not restricted to that. My analysis also offers social critique based on compelling ethical issues that are interwoven with epistemological ones. Both sets of worries are related, in turn, to the methodological concerns I have raised in this chapter.

As I have already suggested, the orientation of my work is decidedly feminist. But the description of the overall project is incomplete without an account of what methods of study might constitute this orientation. The methodology must foster an analysis of relationships between identity, agency, and adherence to ART, which I take to be missing from the conventional methods of study. Statistical analyses cannot offer an examination of the ways in which identity and agency are formed and enacted in the health care system. In particular, the methods I have outlined in the previous sections are unable to address how intersubjective, institutional, and broadly social elements of HIV care are inherently connected to meanings that women from Vancouver’s inner city ascribe to ingesting medicines and participating in the health care system, and how these elements become inscribed upon and within their bodies. My own research practice strives, therefore, to achieve continual engagement and questioning with the common sense, everyday understandings embodied in HIV care, research practices, and health institutions.12

The philosophical analysis I am offering draws upon the empirical research I conducted over a span of fifteen months, in Vancouver’s inner city. Based upon my understanding of ethnographic methodology, I carried out participant observation as well as qualitative
interviewing, in an effort to understand what aspects of women’s access and adherence to HIV care might be missing from conventional quantitative studies. Ethnography provides an opportunity to gain perspectives of differently situated individuals, their interactions with each other, and theorize interplay between individuals, institutions, and wider cultural formations that contextualize their experiences (Mason 1996, 55-57). Rather than individual units of population, data is made up of system of relationships (Leach 1967, quoted in Malkki 2007, 167). It therefore provides an ideal framework for approaching neglected aspects of the access/adherence literature. I say that the qualitative research I have undertaken is “based on” ethnographic methodology, rather than simply asserting that I have conducted an ethnographic research study, in order to recognize that I have not entered into my field work with the history and problematics of ethnography, as practiced by anthropologists (or sociologists, for that matter). I admit that this is not the usual way that philosophical research is conducted and that I am not providing a standard philosophical accounting of an issue that has implications for philosophy of science and medicine, value theory, and biomedical ethics. The interdisciplinarity of the study is a result of my research questions and understanding of critique, and I hope will be read in that vein, rather than as a failed attempt to meet expectations of analytic philosophy (or sociology, for that matter).

With those caveats in mind, let me shed some light on what it was that I undertook for fifteen months (between October 2007 and January 2009), in numerous locations where women living in Vancouver’s Downtown Eastside community might access HIV care: community clinics, a women’s infectious disease clinic, the emergency department and medical ward servicing the inner city population, as well as the dedicated HIV/AIDS ward of the same hospital. I also had the opportunity to spend a substantial amount of time with a number of nurses providing home-based HIV care in the inner city—an alternate model of care that provided numerous contrast and comparison points to the primary and specialist care sites I
Seven HIV-infected women with differing experiences in the sex trade, drug-dealing economy, foster care and corrections system took part in open-ended qualitative interviews. As I conducted research, I became attuned to the ways in which the past is inscribed in the present and came to take up the perspective that Didier Fassin articulates when he writes, “history is not merely a narrative or the sum of competing narratives. It is also what is inscribed within our bodies and makes us think and act as we do” (Fassin 2007, xix). While documenting concerns and on-going issues with the participants’ health, I asked individuals to “tell me about your life,” and to talk through experiences they have had, both related and unrelated to their experience living as a person with HIV.

The scope of my data collection has been much wider than it would be, had I strictly focused on treatment barriers and ARV adherence. Just as with susceptibility to HIV infection, women’s abilities to engage with health services are shaped by social inequity. Larger issues of gender inequality, racism, and poverty are expressed as stigmatization, power differentials, and other forms of social violence that begin long before women seroconvert and play out in numerous social settings, not only those in which medicines are prescribed and taken. As I carried out the research, I came to interpret the ways in which experiences in institutions other than the health system might influence what took place in the clinic or hospital; I also interpreted individuals’ discharging themselves from care (i.e. leaving against medical advice, or “AMA”) as being intimately connected to non-adherence to antiretroviral therapy. By taking on this breadth of scope, and by adopting a life story approach, I have consciously rejected biomedical and behaviouralist models, which I have read off of the standard epidemiological literature.

There are dangers in my doing so—life stories, in a format acceptable to academic writing, can be “muffled and distorted” (Titon 1980, 277), all the more so when the researcher interprets events and actions that are not linked subjectively in the mind of the participant.
themselves. I therefore include reflexive writing, as well as interview and field note excerpts, in an effort to add transparency to the whole of the research process and identify where elements of my own subjectivity as a researcher is located in this work. The reflexive component also serves to quash an attachment to “objective” reality and to underscore (rather than camouflage) the manner in which research practices shape the experiences that are represented in the final text.

The concerns, of course, don’t end there. The process of interpreting life stories and experiences relies on the abilities of participants to verbalize, articulate, and (critically) remember. But the act of remembering, in particular, is of great significance given my overall interest in women’s experiences and in processes of identity-making within systems of medical care and research. The aspects of the life stories that inform my theorizing were not excavated—they are constructed and reconfigured in the social setting of the interview and through the ongoing relationships I had with the participants. As events are coded and reconfigured through memory, it is possible to see how they are lived in a particular time-space relationship and how they are connected to the body and its pathologies. The coding and reconfiguring were processes that I was as much a part of as the individuals telling their stories. Accordingly, at various points in the analysis and writing, I would bring presentations, ideas, and transcripts to different participants in an effort to have them collaborate on this analytic process.

Because not all aspects of inner and social life are easily articulated, participant observation provided a crucially important contribution to the study, given my interest in norms of practice and dynamics of power and hierarchy in health care institutions—thus I chose to document daily routines, non-verbal action, and interactions between individuals in the various field settings. The women who participated in the interviews generously allowed me to accompany them through various aspects of the health care system. For two women, Missy and Carly, this included observation during emergency department admitting and hospital stays on the general medical and HIV wards, as well as accompaniment during specialist and primary
I observed HIV nursing and primary care for the remaining five women, Pearl, Dee, Angel, Pink, and Tina, primarily (although not exclusively) in their homes, whether they were residing in an SRO hotel, supported housing, or on the street. Each of the seven women identify themselves as having Aboriginal ancestry, although the extent to which they described a connection to their Aboriginal heritage varied greatly. Some women have lived on reserve in various parts of Canada, though many have lived in primarily urban settings; some were raised in white foster families, with limited affiliation to their Native heritage. Although not exclusively negative or “traumatic,” the connections that women identified with their immediate families were variable and often tenuous.

Additionally, a number of HIV positive men and women took time to speak with me about HIV services, and about living as an HIV positive individual in the Downtown Eastside, while I was observing medical practice in the primary and specialist clinics they attended. In two primary care sites, this included men and women who took part in witnessed daily medication delivery (“daily observed therapy,” or DOT), as well as women who participated in “women’s only” clinic hours and programs. In the hospital, friends and acquaintances of Missy and Carly also spoke with me while I spent time on the wards. These casual conversations are “evidence” (Malkki 2007, 67) at least as much as formalized, recorded interviews are. I found that snippets of quotes and paraphrased conversations that were generated from spontaneous discussions were often more forthright and revealing, as compared to those in which the presence of the tape recorder limited spontaneity and frankness, acting much like an elephant in the room.

This research also involves “studying up”: health care providers such as nurses, social workers, as well as family and specialist physicians working in HIV/AIDS and addictions care agreed to take part in clinic observation and semi-structured interviews, as did staff members within the local health authority. Like the seven women who offered me their time and stories, the health care providers who became participants and key informants were selected based on my
ability to build relationships with them, and who was interested in the research (often for manifold reasons). As I do not venture to offer any kind of generalizations regarding HIV care, this is not a “representative” sampling of patients, health care providers, and administrators. They are individuals with varying depths of experience in the field, thus they offer differing insights to the social field of study, through their relationship to it, to each other and to others in the field.14

As I became more involved in my studies, I understood my research practice to be a creative and flexible undertaking. I followed up with numerous issues that became pertinent as the observation and interviewing progressed, some of which I did not anticipate examining at the outset of the project. For example, it was only after one participant was sentenced to time in a women’s correctional facility, and my visiting with her there, that I began to think of the ways in which disparate institutions might be connected and linked experientially. This experience, along with my work in an anthropology graduate seminar, informs the discussion “Institutional Memory” in Chapter Four. There were also issues that I found compelling and likely related to my discussion in important ways, but was unable to examine. Thus the explanations that I am able to offer based on this patchwork collection of experiences, are neither totalizing, causal, nor reductionist.

METHODOLOGY, ARGUMENT AND CLAIMS TO KNOWLEDGE

Although my own qualitative research practice has been informed by my philosophical commitments and does not come from an anthropological “will to knowledge,” Edmund Leach’s synopsis of the differences between anthropological and statistical sociological theorizing resonates with the contrast between methodologies that I have offered so far:

Here again we are back at the basic difference of attitude adopted by sociologists and anthropologists toward their raw material. The statistical sociologist takes it for granted that the truth which he is seeking is contained in his questionnaire answers and that the mathematical technique is capable of revealing that truth...it is in the very nature of questionnaire investigation that the “results” tend to err in the direction of ideal
stereotypes. Hence any attempt to investigate, by questionnaire research, the degree of fit between an ideal stereotype and actual practice is a waste of time. (Leach, 1967; quoted in Malkki 2007, 170)

The features I have highlighted within the social epidemiological literature regarding adherence and HIV care reflect the attitude Leach describes. Producing generalizable knowledge requires that bias, tension, and inconsistency (e.g. “outliers”) are removed from study; it is a relief (rather than a loss of understanding) when one sees a regression toward the mean as the sample size becomes larger. As I have begun to discuss with respect to the issue of classification and kinds, the presumption of the legitimacy of a disembodied, objective, “view from nowhere” standpoint calcifies the object-subject (inside-outside) boundaries of knowledge; data that are generated from it are understood as taken-for-granted. This can result in both an inadequate accounting of the fluidity of groupings, an inability to appreciate (methodologically) the performative aspects of identity categories, and the significance of these categories in face-to-face encounters between individuals with different social, economic, and cultural positionings.

Charles Taylor writes that there appears to be an irresistible temptation to fit the “sciences of man” into a paradigmatic empiricist model, constructing both the questions regarding human life, and their answers, so as to generate data whose validity cannot be challenged by reinterpretation (Taylor 1971, 184-185). Claims to authority are based on a lack of bias, such that apparent differences between groupings of analytic units and outcomes of interest are thought to reflect actual differences and processes in the world. This type of statistical study offers what is as close as possible to a causal explanation for the question of interest. As Michel de Certeau suggests, with respect to realism and historical analysis, claiming to represent reality camouflages practices that determine the representation presented (de Certeau, in Scott 1991, 777). The oft-cited limitations of cross-sectional study fail to address the rhetorical implications of causal-type explanation and claims to representativeness,
particularly when studies suggest that a lack of direction of observation ought to be addressed by creating new prospective cohorts.

In contrast to this, ethnographic writing employs personal relationships in its production of knowledge and strives to maintain particularity even as experiences are objectified and textualized. Similarly, my philosophical analysis of the qualitative research I present preserves the particularity of the data and aims at generating “partial truths” (Clifford 1986, quoted from Kaufman 2005, 328). Specifically, *particularity* entails: the location of the object of study and the knower in relation to one another, the historical moment within which the object of study is understood, the social logic brought to the research, relationships between phenomena of interest and other events, objects, various power relations underpinning the research, the problematics of the discipline one enters the field of study with, etc. Allaine Cerwonka writes, “not only is it impossible to transcend these particularities, but they are necessary (and desirable) ingredients for organizing, interpreting, and making meaning of a phenomenon or text (Cerwonka 2007, 26). “Thick descriptions” are produced by the presence of particularities making up social discourses under study within the final text.

As in ethnographic modes of interpretation, I do not offer generalizations from my findings. The arguments I offer in the following chapters are steeped in their particular time-space relationships, even as I attempt to link very detailed local phenomena to wider global and historical processes. This is in contrast to sociological statistics, which homogenize data in numerous ways in order to interpret the significance of variables and make subsequent generalizations. Early in my preparation for the work, I would often have to grapple with questions regarding my ability to make knowledge claims, when I was proposing to engage with a small number of participants. “Would it not be better to interview fifty people, rather than five people ten times?” was a standard query. The theoretical connections I make, between mundane, minute phenomena and larger global processes are a result of my length of engagement in the
field study and thickness of descriptions I am able to give. The local and immanent quality of the data is maintained, as opposed to being a reflection of a larger universal or transcendent category, as is the case with widely sampled, homogenized data.

A deep examination of local, everyday, and common sense understandings and meanings, provides an opportunity to convey discontinuity and heterogeneity of data. Because maintaining particularity forecloses the notion that individuals or relationships that make up the data I present are somehow interchangeable, a study could focus on a small number of individuals, even those who are “outliers,” and still offer theoretical insights regarding the phenomena and the processes interrelated to it. In contrast to the statistical data of social epidemiology, the data I present are neither fungible, nor ahistorical, nor individual, at the level of acquisition, textualization, and consumption.

I also enter my study with an anti-positivist, anti-reductionist orientation to knowledge production, given that I take knowledge production to be a flexible, creative, social, and historically influenced process (Cerwonka, 2007, 23). Following Joan Scott’s discussion of what kind of evidence one might take from experience, I want to also make clear that I am not suggesting that my recounting of women’s experiences in the health care system is a representation of a singular “truth” about health care services, non-adherence, or life in Vancouver’s inner city. As Scott suggests, taking the stance that one is representing “reality” is problematic in a number of ways, in particular because it “reproduces rather than contests given ideological systems” (Scott 1991, 778). For as much detail and richness as is provided by the long-term study of a given set of phenomena, its interpretation is necessarily underdetermined. When Geertz states that “as in any discourse, code does not determine conduct, and what was actually said need not have been” (Geertz 1973), he points to the idea that an object of knowledge cannot simply be found, existing in the world—it is constituted and reconstituted by its inscription in text. But in being “made,” it is not the case that data simply illustrates social
processes as they have been previously defined (Cerwonka 2007, 17). Nor is it the case that one receives unadulterated “data” and builds ethnographic theory from the ground up. And while interpretation suffuses the entire practice of ethnography, it is still a **practice**—theoretical insights require a “knowing how” as much as a “knowing that.”

Lisa Malkki and Allaine Cerwonka describe this process as one of “tacking” between theoretical understandings and the insights gained from a long-term engagement in the field. They understand the interpretive process as a continual movement between having experiences in the field sites and organizing that experience for subsequent analysis with one’s theoretical affiliations and problematics operating, at times in the background, at times in the foreground. \[21\] Linkages can then be made, between giving a reading of one’s empirical work and connecting these interpretations to broader social systems, political events, and conceptual frameworks inform one’s social space as well as the theoretical concepts that one inevitably enters the field with.

Local events and global processes can be seen as another “system of relationship” (Malkki 2007, 166), one that can offer a different level of understanding of the phenomena (i.e. beyond its immediate interpretation). It is within this kind of relationship that intersubjective meanings can be understood. Moreover, these levels of understanding are not necessarily representative of a singular explanatory logic, hence the offering of “conditions of possibility” for understanding an object of study, rather than a reductionist, causally-oriented explanation. Throughout my philosophical analysis I have been careful to remain “epistemically humble,” but I felt it was also important to foreground this work with the qualification that I am offering here an **alternate** (but not singular) lens through which to view the problems around access and adherence to treatment. My hope is that this different view might radicalize conventional views of this issue, even if only for a moment.
PRAXIS, ETHICS AND INSTITUTIONAL REVIEW

In my description of my approach to qualitative methodology, I attempted to highlight how the research and the knowledge that was constructed from it was an interpretive process. Likewise, trying to establish and then carry out what it means to engage ethically with research participants was an on-going process, albeit one that generated an enormous amount of self-doubt and guilt. The research ethics boards at UBC-Providence Health and Women and Children’s Hospital approved the study, as did the Vancouver Coastal Health Authority Research Institute. The consent forms and procedures that I followed at their behest did little to assuage the feeling that I was exploiting individuals’ often challenging and difficult life situations.

An adequate analysis of the limitations of institutional ethics review would produce another dissertation entirely, so I will limit myself to a few notes on some of the issues that could be raised here. Coming from a feminist orientation, the most burning issue that haunted me throughout the work was the enormous differences in power between myself and the women I was working with on the project—women who allowed me, on a regular basis, to accompany them during invasive medical examinations and private conversations with health care providers, offered their stories to me, requested honoraria, spare change and food from me, wanted a friendly face or non-judgmental ear, and sometimes needed more practical assistance contending with the logistics of government bureaucracy. I tried as far as possible to allow the participants to shape the course of our relationships. This meant that for two women, on-going advocacy and practical supports were part of our time together. 22 One of the biggest challenges has come as I’ve needed to step away from my daily interactions in the community and return to my academic obligations at the University. Thus the relationships continue to be negotiated.

I was regularly unsure of how the participants’ viewed my role with them, particularly when they introduced me to others in ways such as a “medical student” or “worker,” sometimes “my friend,” but rarely (if ever) as a researcher. My attempting to establish that I was
conducting research was often met with an admonishment that of course they knew that, why did I keep asking, such that I eventually stopped pointing out the apparently obvious. It took time for me to realize that the women I was spending significant time with needed to be able to negotiate and present our relationship to others in a way that make sense in their daily experiences and that wouldn’t arouse suspicion or criticism from others in the community.23 Highlighting my status as a student also enabled some participants to indicate how they were socializing me, such that we were both object and subject in this mutual enterprise of knowledge production. This joint, simultaneous positioning makes for what Stephen Richer (1988), quoting Dumont (1978) and Rabinow (1977), identifies as an intersubjective practice. This was the major consideration for adopting the methodology that I did, in wanting to address intersubjective meanings and relational aspects of health discourse. But for as much as I attempted to keep the collective process going, in the end I am the author of the final product—participants receive acknowledgments, but I will likely receive an advanced degree.

Our different social positions also led to deep concerns with respect to consenting to research. Within research ethics, consent to participate in research is tightly connected to respect for autonomy (Dodds 2000, 213-219; Beauchamp and Childress 1994, 121). Given that I was conducting the work to think more deeply about women’s autonomy, it’s no surprise that the process of on-going consent to participate was one that I examined at great length, both internally and with my research participants. Getting to know participants and establishing rapport before introducing consent forms and the administrative elements of research is standard practice and may be a more appropriate way to give potential participants time to judge whether they want to take part in the research at all. But it also generated a sense that I was potentially exploiting friendships I had established.

The worry about exploitation was exacerbated by the fact that the women who took part in interviews and observation were substantially impoverished and often faced inordinately
difficult life circumstances. The honoraria were important contributions to their incomes. When discussing follow up interviews, women would sometimes implore me to meet with them sooner rather than later, saying that they needed an interview. Was it even possible to ensure (as best as possible) that we were creating a space where they could be autonomous agents, where our relationship wasn’t only a commodity? These issues were not restricted to the women taking part in the work. I would feel as though there was a rock in the pit of my stomach the times I heard health care providers ask, “remind me again, what it is, exactly, that you’re doing?” This left me to wonder whether I somehow hadn’t been manipulative in my entering the field sites, and brought about a continued engagement with the ethics of self-representation.

As the work was wrapping up, I began to compare this experience of on-going consent with the consent procedure that took place in a different research project I had assisted with as a new graduate student, where I was responsible for obtaining formal consent from potential survey respondents—consent in that setting was a temporally constrained event. Certainly people were informed that they could withdraw from the research at any time, but once they were “consented,” there was nothing else to do but administer the questionnaire. Contrasting these experiences, I saw how autonomy was indeed bound up with negotiation and how the relationships between various agents as well as the framing of a given issue—consent as process versus procedure—could make those negotiations possible.

My time carrying out the research was fraught with other ethical challenges; it was what Allaine Cerwonka so appropriately refers to as a “nervous condition” (Cerwonka 2007, 38). The ways in which women’s daily lives are organized around informal economies in the Downtown Eastside and the regularity of violence (such that it became almost mundane), also generated ethically challenging situations that I was often unprepared for and that were certainly not part of the standard IRB considerations. Accompanying one woman to a specialist appointment, I ended up holding one of her crutches as she threatened a woman on the street with the other one,
shouting about an argument over a mutual friend who had been ripped off, each blaming the other for the lost money. Not wanting to be involved in the fight, I backed away—until the woman I was with was punched in the head and fell backward into my arms, leading her assailant to approach me, fists raised, instructing me to “drop her” or I would find myself involved in the fight as well. I didn’t drop her, the fight did die down after further shouting, and the whole thing was something of a bonding experience, no doubt influencing the course of our relationship.

A number of times when another woman was admitted to hospital I was asked by friends of the participants if I might be able to pass along “notes” and packages of “cigarettes,” hinting that they might contain illicit substances. In those instances, I relied on the participant to reinforce with her friends and acquaintances the boundaries of her relationship with me. The challenge of these situations, aside from wanting to maintain a good relationship with the woman, was that I knew that whatever was in the notes or cigarette cases was likely to help her remain in hospital. My subsequent decisions regarding my avoidance of certain interactions in the field were informed by these dilemmas and shaped what has been possible to say about the research questions themselves. I faced different sets of challenges working with health care providers. In those cases, I felt the need to be cautious about what I might present as data, given that people’s jobs and reputations were connected to my work. Moreover, certain programs are more vulnerable than others, in terms of on-going funding and support. Critique has downstream effects and I had to think what some of those might be politically, for all of the individuals who were generously working with me.

All of these considerations ought to make apparent that, as with my concerns regarding methodological individualism and adherence literature, the ethical and epistemological issues I faced were intertwined. My hope for the ethos of the research was that I might be able to carry out work that participants found engaging, and that offered them a space to say something that
they found meaningful. My epistemological goals were to examine the interpersonal and institutional dynamics of HIV care, examining how women navigate the health care system, and the relationship between their health negotiations and the wider context of their everyday lives. Given that the goals of a feminist analysis are inherently political, I hope that by drawing the connections between selves, institutions, and discourse, the project is able to make a necessary and important contribution to the field and to the experiences of those who took part.
Pains and pleasures, hopes and horrors, intuitions and apprehensions, losses and redemptions, mundanities and visions, angels and demons, things that slip and slide, or appear and disappear, change shape or don’t have much form at all, unpredictabilities, these are just a few of the phenomena that are hardly caught by social science methods. It may be, of course, that they don’t belong to social science at all. But perhaps they do, or partly do, or should do. That, at any rate, is what I want to suggest. Parts of the world are caught in our ethnographies, our histories and our statistics. But other parts are not, or if they are then this is because they have been distorted into clarity.

(Law 2004, 2)

My discussion of statistical measures and standardized psychological constructs used to investigate reasons for non-adherence to therapy has launched an analysis of the epistemic limits of conventional research practices within the domain of adherence to HIV/AIDS treatment and care. Unlike actual drug use practices, which are temporally varied, heterogeneous, and intertwined with the need to work within informal street economies (and not merely related to a physiological or psychological needs for a particular substance), the deployment of the IDU classification within research practices helps to produce the image of a singular, coherent, homogeneous category. The representative members of the group are seemingly rationalized appropriate objects for which data can be collected, policies generated and interventions rolled out. An acronym (i.e. IDU) that is meant to refer to a specific drug use pattern slides easily into a (wider) representation of a kind of person—the “drug user.”

In many ways, adherence discourse operates in a fashion parallel to that of the IDU classification: both suppress the diversity and fluidity of phenomena in favour of offering clean, unified categories. In this chapter I argue that while different meanings are attached to term adherence and mobilized within different clinical and research spaces in relation to the goals of those working within them, these differences are subsumed and obliterated by the conventional views of health decision-making that rely on a model of rational action. Within conventional quantitative adherence research, a singular story concerning what constitutes adherence to ART
is told; this story is taken up to varying degrees within medical encounters. The result is a depiction of non-adherence as a failure of individual agency and the endorsement of a wide (albeit tacit) presumption that such failures will be adequately corrected by experts within the health care system.

First, while the conventional view seems to provide a tightly scripted understanding of what adherence is, the day-to-day mobilization of adherence by various health care practitioners is decidedly more diverse. Hence, I discuss the contradictions, variabilities, and uncertainties that are often left unexplored in much of the quantitative social science research. Within quantitative studies, data are “cleaned” \(^1\) in order to produce a consistent object of knowledge that can be studied and subjected to policy intervention within a biomedical reality. The smoothness of demographic categories on paper belies the fragmented identities and fluid movements of the people and actions so categorized. What is of further interest are the ways in which the data cleaners are invisible in the process of data analysis, such that the data appears to fall easily into variables and categories, rather than having been mashed, forced or manipulated in. This is the monological model of knowledge production at work: if nobody is doing the mashing, there is also no need to consider what relevant aspects of data are produced intersubjectively, or how the process of knowledge generation is an interpretive rather than descriptive activity.

Examining women’s experiences in clinical settings, this chapter responds to the first of the questions posed early in the research—what do the experiences of women reveal about non-adherence to ART? The refusal to clean my investigation of adherence of its inconsistencies and contradictions constructs a more adequate body of knowledge about the phenomena. It will also, over the next two chapters, offer a way to see how stereotypes, figurations, and schemas concerning those who are understood to be predictably non-adherent to therapy operate within conventional research practices, which carry over to the domain of clinical care.
NON-ADHERENCE AND FAILURES OF AGENCY

Field notes, October 14, 2008

I get a phone call from Missy, announcing she’s in the hospital again, and I head up for a visit. She’s been admitted for cellulitis and her doctors have re-started her antiretroviral medications. We’re going to do another interview today. As we begin, she opens the drawer of her bedside tray table and rattles through a number of containers, pulling out two syringes filled with a thick yellow paste—so thick that it coats the sides of the container it’s in. I find out later, from a ward nurse, that it’s Nystatin, an oral thrush prophylaxis. It’s meant to be squirted into the mouth using the pressure of the syringe plunger, so that none of the thick yellow goop gets wasted. If it were in a normal medication cup, it would just cling to the plastic. In the past, I’ve seen her nurses loading the paste into the syringe; it often prompts them to remark how nasty the stuff is, that they wouldn’t want to take it either. Missy says it tastes bad, it looks like kid’s paint and that’s what it tastes like too. Chalky. She throws the tubes into the garbage, placing a paper towel that’s already in the trash can over top of the pile, covering the syringes. She tells me, “I don’t even know what it is.” I tell her I think it’s part of her prophylaxis meds. “I don’t know. I hope not… I guess I should be taking them,” she says. “Instead of sticking it in the drawer?” I ask. She tells me that she has asked the nurses to make sure she takes it, because she won’t otherwise.

In conventional accounts of health behaviour, Missy’s throwing out her Nystatin or hiding in the garbage so that her recalcitrant act wouldn’t be discovered, are actions that would be described as non-adherent. In Missy’s case, the medication looks and tastes bad (not even the nurses would want to take it), suggesting that difficulties with ingesting medicines are significant. Clinicians, as well as researchers working in the field of HIV/AIDS treatment and care, discuss the significance of issues such as the size of pills, difficulty swallowing medications, number of pills, and challenges with timing of medicines (some requiring food, some an empty stomach, multiple times in a day). When medications produce side effects (e.g., nausea, gastrointestinal upset, changes in body fat distribution) or require additional medications to control, the antiretroviral regimen quickly becomes onerous and difficult to establish as a daily practice (Stone et al. 2001, Bartlett et al. 2001, Conrad 1985). Side effects are typically more numerous in women and challenging to manage (Feinberg and Maenza 2005). They are logically seen as an important factor in sex-based differences in adherence, which may be ameliorated by health professionals. In line with views of rational action, medication beliefs
(whether it does or doesn’t work; what exactly it works for) are associated with adherence to therapy in much of the HIV adherence literature (Boyle, 2000; Horne et al, 2004). Pharmacists, practitioners, and medical literature see patients as needing to be “coached” on expectations around medication issues so they understand the importance of taking medications even in light of difficulties like pill size or side effects and have a set of beliefs about medications that are integrated in their larger value systems, enabling them to autonomously carry out the action of pill-taking.

Health decision-making theories suggest that people living with HIV must (a) be motivated to take their medications on a daily basis in order to be adherent to therapy, (b) be willing to prioritize treatment in order to persevere with a regimen over time, (c) have the confidence (both in oneself and in the health care system) to take medications, and (d) understand how treatment works, in order to contend with challenges such as side effects. Thus, motivation, stable preference ordering and follow-through, as well as trust and adequate knowledge must be in place for health-related behaviours, including the ingestion of prescribed medications. This view of adherence functions on the ward and in clinics as it does in adherence research. Missy’s health care providers were not convinced that she had the necessary combination of beliefs and desires concerning either her ARV or her chemotherapy regimens, nor a willingness to change with respect to substance use (including a number of failed attempts at methadone maintenance therapy). Her request that staff administer the medication also seems to support a common assumption that drug users require firm and structured interventions, such as directly observed therapy (DOT) programs.

Patients themselves sometimes endorse aspects of the conventional view of adherence, telling me that it was difficult to follow through with taking medicines when they couldn’t see or feel that something was wrong. Dee described this by saying:
It’s foreign to me to be taking pills. I can’t see that something’s wrong. When I’m actually sick, that sick, then I can say, okay, okay I understand what they’re for. But to understand what they’re for when you can’t see sick, our brains aren’t used to [that]…especially as addicts.

Dee speaks to the importance of patient beliefs in pill-taking, as well as a “common sense” idea that drug users just don’t reason properly when it comes to following through on health decisions, especially ones in which the benefits are not immediate. Dee’s statement surely captures some of what is significant about adhering to medication—in this case, the immediacy of illness being significant for the motivation to take medication.

My contention is that the conventional model of adherence, studied by way of social epidemiology, is only capturing part of what is going on, some of the time. Survey instruments that examine patients’ reasons for non-adherence endorse this “common sense” view, by examining the influence of factors related to rational decision-making and cognitive function: forgetfulness, being asleep during dose time, using drugs/alcohol, too complicated a regimen, changes in schedule/routine, and so on (Cheevers 2005). But overlooked in the analysis of these factors is the survey setting is very often an interpersonal interaction; responses are influenced by the conditions under which the questionnaire takes place and may well reflect performative and strategic aspects of identity. By failing to examine the inconsistencies and contradictions in individual responses (especially those that, while present, do not achieve statistical significance), the literature tends to uncritically adopt a view that Dee expresses and that Missy was faced with from health care staff: that following through with medical advice is always rational and that drug users have problems with rational action.

On the conventional account, non-adherence is a failure of rational agency and individuals who are consistently and predictably non-adherent are construed as non-agentic, due to certain types of illness, mental capacity, and externalities such as addiction. Likewise, drug use is frequently depicted as a loss of control over one’s faculties and is commonly attributed to
untreated mental illness. As a contrast, substitution therapy is thought to stabilize patients, the primary example of this being the use of methadone for opiate addiction. With a long half-life, methadone is promoted in terms of its ability to block withdrawal symptoms as well as the euphoric effects of opiates (Childress et al. 1991, 167; Nosyk and Anis 2009, 1093). Both euphoria and withdrawal are conditions contrary to norms of rationality; in medical discourses, this is defined by the more euphemistic term, “stability.” Given the circumstances and depictions of Vancouver’s Downtown Eastside—unstable housing, mostly informal, under-the-table or illicit economic opportunities, populist rhetoric concerning the ubiquity of untreated mental illness—drug using individuals from the community are understood to simultaneously require such stabilizing therapies and at the same time be unable meet the criteria for clinical stability. As I discuss further on, it has been argued that what the programs in fact offer is a way to ensure some semblance of control over what are seen to be the unruly activities of those living and working on the street.

The imagistic and figurative content of stereotypes and tropes of these drug users sits in opposition to the social imaginary of rational, autonomous agency—even for those who are partaking in accepted forms of addiction treatment. For example, in a hospital workshop concerning addictions management geared toward new nurses, which I attended in 2009, the workshop leader (an addictions nurse) pointed out to the audience that when drug users aren’t yet motivated to stop using, they likely don’t realize, or have the right beliefs about drug use (i.e., that it’s bad for them) and thus they aren’t able to stop using. Without the right sets of antecedent beliefs, no action would be taken. Moving toward recovery, by going through detox, cutting down on drug consumption, using substitution therapies, and so on, are conceived of under the contemplation-action model as being motivated by a mental state with propositional content. Stopping or decreasing drug use is presented as the reasoned response to the information that drug use is bad for your health.
A rational actor model enables the singular story to be told: adherence, following this model of action, is endorsed by practitioners and researchers to be a straightforward, singular phenomenon. It is about getting all of the combination therapy into someone’s body, 95% of the time, in order to achieve viral suppression.\(^7\) Health behaviour theories that explain what adherent behaviour consists of converge with forms of non-adherence that are depicted as failures of rational agency. Just as on-going drug use is seen as contrary to rationally motivated behaviour, models of adherence presume that following through with medical advice is always rational; it is no surprise then that non-adherent women are frequently defined as a group, by their use of illicit substances. There is a smooth integration of the observation that drug users have difficulties with adherence (though no difficulties reporting to researchers on this “fact”); the populist understanding of drug use as irrational and irresponsible makes it easy to comprehend how drug use functions as a cause, correlate, and proxy measure of non-adherence in practice. The model is also helpful for generating interventions and recommendations for health care providers to carry out.

**MAKING A MESS OF THINGS: ADHERENCE IN PRACTICE**

Consider now that the Nystatin that Missy hid in the garbage isn’t actually part of the combination of medicines that make up highly active antiretroviral therapy. Why should refusing that medication be framed as non-adherence? It likely wouldn’t have been captured by surveillance data on antiretroviral adherence, had this been part of a clinical research project—in those instances, prescription refill of *strictly* antiretroviral medicines in considered. But by virtue of the medication being connected to her overall health in the context of HIV infection, as well as it being part of a recommended set of actions given to her by a representative of the medical system, the disposal of this medication is taken in the clinical setting, both by Missy and her health care providers, to be indicative of an overall picture of Missy’s non-adherence to ART.\(^8\) Hence, she hid the unused vials. Likewise, the concerns about Missy’s leaving against medical
advice during the course of treatment for cellulitis is part of her wider “reputation” for non-adherence to medical advice with respect to chemotherapy as well as antibiotics and is taken, within on-the-ground medical practice, to have relevance for adherence to ART.

The Nystatin story points to the ways in which adherence is understood somewhat differently in the different physical and rhetorical spaces where knowledge about it is generated. Within research practices, a relatively narrow set of parameters determines whether someone is part of the “non-adherent patients’” group, adherence measures rely on calculations based on prescription refill rates as well as patient self-reports. We can compare this to how the concept of adherence is mobilized in community clinic settings. For those who participate in directly observed therapy (DOT) programs, a medication administration record (MAR) marks a witnessed ingestion with a tick, a red “O” if the patient had to have their medications taken to them by outreach services, or an “x” for a missed dose. Those filling in the charts are fallible and ticks may be missed or added in erroneously. As Denielle Elliott has described in her ethnographic work on directly observed therapy in the community, the overworked and understaffed nursing practices of many DOT programs results in nurses losing track of attendance in programs, resulting in idiosyncratic record keeping that is not accounted for in traditional health research methods (Elliott 2007, 24). The nurses doing the ticking are rarely acknowledged as part of the action. Within a clinical environment, the MAR may matter to the nurses and coordinators directly involved in DOT programs (e.g., in determining who needs an outreach visit, who might require further supports, who might not be a suitable candidate for the DOT program because of too many missed visits), but the MAR sheet is not the primary concern of physicians contending with HIV. Thus there are also dissimilarities between clinic and research/surveillance.

In further contrast to research practices, encounters between physicians and patients predominantly measure adherence by way of viral load—if viral load is undetectable over a
series of blood draws, and it remains that way, a patient is believed to be adherent. Patient self-reports of adherence have little utility, although clinicians and pharmacists do heed reports of challenges with a particular regimen and the side effects from medications. Interestingly, there are other relevant pieces of information, which sometimes offer a proxy measure of adherence within the clinic. These are generally much wider than proxy measures implied within research practices: vaccinations and blood work are important, as is whether someone is coming in at the right time for their methadone script and seeing the same health care provider, if they are keeping weight on or not, or if they are quietly sitting in the waiting area or causing disruptions with the administrative staff at the front desk.

Carly, for example, had been prescribed methadone and antiretrovirals over the previous fall (2007) and had not been taken them. Her reputation did not bode well for her health care providers’ expectations of her, regardless of her own confidence and interest in treatment. Thus when she asked her physician at one visit about re-starting medications, it was suggested that she might be better off to wait until she was more “stable.” Her physicians and nurses wanted to see that she could institute various changes before they were willing to engage with her—they recommended that she think about going back to see the drug and alcohol counselor, that she try harder to pick up her methadone script on the same day each week, rather than coming in when it was convenient for her. Presumptions of drug use, inconsistency with respect to the health care provider who she was seeing, whether she was making it to counseling—all of these relate to patient adherence in the clinic. There is some overlap with research, insofar as there is an association between non-adherence and drug use; this overlap must be solidified, in order to stabilize the views of adherence as being one and the same thing, in these two different domains.

The hospital has yet another set of concepts around adherence that are mobilized, some of which overlap with community clinics or research measures, and some of which are unique to that setting. On one level, adherence is taken for granted if the medication cup goes into the
room full and comes out empty; paradoxically, it is taken for granted that the patient is non-adherent overall, if drug use is thought to be an on-going issue. When both Missy and Carly found themselves on the hospital ward for extended stays, they each felt as though they were being scrutinized by hospital staff and were considered non-adherent to care during the times they left the ward to go to the smoking balcony. Whether or not they were taking all of their medications, or consuming their ARVs, yet tossing the Nystatin, they felt they were treated as though they were going to use each and every time they were out of eyesight.

When speaking to me about each woman’s ability to remain hospitalized and in adherence to medical advice, I would be told “you know, she’s been off the ward a lot,” as a tacit indicator that they were using and explanation of the health care providers’ lack of confidence in their ability to remain engaged in health services. Presumptions of drug use tend, more likely than not, to escalate tensions between staff and patients, sometimes leading to the very circumstances (an angry departure against medical advice) that the staff were concerned about. This would often mean worsening health outcomes, missed methadone doses and unfilled ARV prescriptions—forms of non-adherence that are conventionally measured through surveillance data. Those departures would also be inscribed in the medical notes and referred to at the next admission to the ward such that they would be known as prone to self-discharge and physicians and nurses would adjust their behaviour and expectations of outcome accordingly.

Insofar as it is taken by health care providers to be a reflection of non-engagement in the health care system, a reputation for leaving “AMA” offers a reflection on the ability to adhere to an ART regimen. As leaving AMA is connected, in the minds of health care professionals, to substance abuse, there is a slippage between presumptions of drug use and presumptions of non-adherence, whether or not that is the case at any given time. If, as the medical literature suggests, drug use is associated with non-adherence to ART, it is not a substantial rhetorical leap to understand how drug use becomes a marker or stand-in for non-adherence in clinical practice.
Being out on the fourth floor balcony or having a past history of self-discharge on welfare day therefore serve as hospital-based indicators of non-adherence.\textsuperscript{11}

In some instances, health care providers working in outreach and home care settings offer a different view on adherence yet again. Being able to have a conversation with somebody who was seen as hard to reach, or having someone open their door to the worker and accept a cigarette or be taken to an appointment, were all indicative of “engaged” behaviours that bode well for adherence, whether or not someone was even on antiretroviral therapy at that time. Similarly, one of the HIV home care patients I observed would sometimes, for instance, skip certain medications during a particularly difficult week, but she would still understand herself as nonetheless “engaged” in the system and adherent to medical care, insofar as she continued to welcome the nurses into her home, extend the usual courtesies, accept her diet supplementation and possibly take certain other pills from the pillbox that week.\textsuperscript{12} Her nurses would attempt to encourage her, that if she was going to “cherry pick,” she ought to take the ARVs, and leave behind the sleeping pills or anti-psychotic medications.

While the nurses still understood adherence to be about getting the ARVs into the patient’s body, their approach didn’t take adherence to be about a narrow set of measures; it included an understanding of this particular patient’s need to negotiate medication ingestion. In contrast to the antagonistic dynamics that develop around drug use in hospital settings, this approach to thinking about adherence is more likely to ensure that CD4 counts remain high and that other forms of pathology are promptly recognized and dealt with. Of all the possible spaces where HIV care took place, those that were the closest to people’s day-to-day lives (HIV home care nursing, non-profit community clinics that provided daily meals, food banks and outreach services to its HIV-positive members) seemed to have the most success in maintaining long-term adherence amongst patients, given that adherence in such locations was both holistic and nuanced.\textsuperscript{13}
CLEANING IT UP: HOW MESSY DATA BECOMES A SINGULAR STORY

How is it that the different meanings of “adherence” in various locations are amalgamated? In order to achieve a relatively unified view of adherence and of drug users, certain practices and inconsistencies need to be removed from the data sets, mashed into the right form, or ignored altogether; certain voices that speak to issues surrounding adherence to ART must be muffled, while others must ring loud and clear. Annemarie Mol, investigating lower-limb atherosclerosis in the Netherlands, has examined how a seemingly singular condition has numerous assemblages of methods and practices mobilized around it, related to attempts of treatment and diagnosis. Mol argues that while medical inquiry and intervention (in the pathology lab, in the radiology department, in the surgical consult room) may produce a single reality that “is” atherosclerosis of the lower limb, it does not necessarily happen (Mol 2000; see also Law’s discussion of Mol, in Law 2004, 45-59). Within different practices, the representations (atherosclerosis for Mol, adherence in my case) are enacted in numerous ways that allow them to be rendered as objects of study; sometimes these representations converge, sometimes they do not.

In instances where practices and representations fail to neatly converge, understanding something like atherosclerosis or adherence as a singular phenomenon requires that differences across time and location not be represented. To see something as a singular condition may in fact require the denial of the variability surrounding its interpretation on the ground. Not only can this reinforce monological epistemic politics—whose voice is heard as an authority on the issue or whether dissent is taken seriously—failing to see the variability and multiplicity of phenomena may mask aspects of the issue that are pertinent for treatment interventions or policy recommendations. Subsequent recommendations in HIV/AIDS programming may be inadequate if the singular story about adherence misses relevant information concerning the phenomenon.
For many other women I spoke with, wide ranging experiences in different parts of the health care system influenced their actions (often taken by providers to be indicative of non-adherence) and shaped what was subsequently achievable with respect to service utilization. For instance, in hospital settings, challenges related to the ability to manage withdrawal and pain while on the hospital wards and the difficulties faced with addictions services were key issues. In community settings, the conflict that exists between following through with appointments as well as medication ingestion and the ability to generate an income through dealing or other illicit economies was particularly relevant. Across a variety of locations, the problems generated by a continued sense of surveillance, lack of privacy, and the feeling of illness representing personal failure often translated into the sorts of actions that would eventually be tagged as “non-adherent,” from the clinical as well as conventional research standpoints.

**TAKING APART THE RATIONAL ACTOR MODEL OF ADHERENCE**

Understanding non-adherence to ART means looking at more than why someone does or does not ingest a particular combination of pills. Peter Conrad suggests that the everyday experiences of illness and suffering (medication and therapeutic advice being only one part of that) constitute a more relevant domain of investigation, rather than a focus on adherence or compliance *per se* (Conrad 1985, 29-30). Non-adherence must be understood in light of the purposes and functions of those who mobilize the concept in specific locations. It must also be analyzed with regards to the function that the rhetoric of drug use, transgression, and deviance plays in the construction of knowledge concerning what it means to be non-adherent and concerning those who are thought to be predictably so. In order to examine adherence from the perspective of lived experience, it is necessary to suspend a widely held belief that precisely following through on medical advice *just is* rational patient behaviour.
I. LACKING MOTIVATION: CONTROL AND INTERVENTIONS IN ADHERENCE

Given the components of the conventional view of adherence outlined in Chapter Two, it is not surprising that the research wedded to a rational actor model depicts a strong relationship between indicators of drug use and non-adherence. As I have discussed, the “common sense” view of what drug users are like is opposite the view of health behaviour as thoughtful, reflective action. The language of addiction reflects this opposition as well—continuing or maintaining drug use is associated with not contemplating or understanding the negative impact of drug use on one’s life. Likewise, drug users were frequently depicted by health care providers I spoke with as childish and irrational, unable to carry through with actions that are within a scope of reason. The model of behaviour change that underlies this view seems to presume that recognizing the validity of an assertion (“drugs are bad for your health”) means that one has reason to accept it, which is itself a recognition of a reason for wanting to accept it; thus reasons motivate (Searle 2001, 176).

In an effort to contend with the association between frequent drug use and non-adherence to ART, it is common practice in the Downtown Eastside community to link methadone to antiretrovirals in a daily dispense format. The use of methadone as an adherence facilitator presumes the fidelity of the relationship between drug use and non-adherence to therapy. Methadone is often seen by physicians as a “draw,” something that a person desires, which will be willingly consumed each day. Studies from Vancouver and Baltimore looking at eligible HIV-infected injection drug users found that failure to receive medications was associated with not being reenrolled in addiction treatment (Celentano et al. 1998; Strathdee et al. 1998). Quite reasonably, antiretrovirals are then dispensed at the same time to ensure that those too are consumed.

But nurses working in the community are quick to point out the limitations with methadone linkage, suggesting that for some patients, taking their ARVs in a public place along
with their methadone is unacceptable, while others have a relatively easy time buying street methadone to contend with being dope sick. Moreover, uncritically accepting the appeal of linking methadone with ARVs means ignoring (1) how drug use itself functions as a coping strategy that can be quite effective in the short term (2) how drug use relates to one’s sense of control over oneself, and (3) that patients vary over time in their desire to take part in substitution therapy for addictions, particularly given the demands of such programs.

First, it is important to consider that it is not merely the case that partaking in illicit substance use is a result of failures of rationality or agency, which then lead to non-adherence. Drug use can also function as a coping strategy. Talking about living in the inner city and using drugs, Missy said to me:

*I’m fucked up…I just get down there, and the dope, and I don’t have to think about any of it. My mom is taking care of my kids, my kid, I’ve got another kid in Vancouver that I’ve abandon…well, I don’t have. And I’m in so much pain.*

Missy’s drug use is related in many ways to pain—from cancer, from cellulitis, from HIV, from her relationship with family—but it is also connected to the meaning of her illness. HIV and ongoing drug use are internalized as kinds of failing that are entwined with one another. Inasmuch as using heroin will let her get away from things for a while, it is a buffer to the dynamics of suffering, which includes the relentlessness of health services and the seriousness of illness that is unlikely to be part of a narrative of health restitution. Moreover, drug use enables her to cope with the demands of dealing—her main source of income outside of her disability benefits. She has to take opportunities to work when they arise. Needing to sleep might mean that she is refused further work. The same thing happens when individuals (mostly men) have opportunities for under-the-table construction work—they need to stay awake and crack cocaine is commonly used to help with this. But drug use is rarely understood in these terms, by health care providers, researchers, or wider society. Drug use is generally taken to be equivalent to non-adherence, rather than a response to the conditions that generate non-adherence.\(^{14}\)
Importantly, my point isn’t to say that drug use has *no* impact (or a good impact) on following through with medical care—it is simply to say that the relationship is shifting and much more complex than it is made out to be.

It’s also worth thinking more concretely about the ways in which women from the community lack control within medical settings and the role that control plays in the dynamics of drug use. I hope that this will demonstrate how women’s reactions against care should not be so quickly brushed aside as overly emotive or irrational, or re-interpreted as merely an excuse to refuse care in favour of drug use. Trying to exert control in a hospital setting when one does not want a procedure to take place, or wants it to occur differently, often means being seen as non-adherent. In terms of an ability to alter conditions under which procedures take place, women are often limited to disrupting the procedure (and deemed unruly), being unavailable (and presumed to be using drugs off hospital grounds), or leaving against medical advice.

Missy described an encounter with a radiology technician:

> “I swear, it was like she was trying to hurt me; “you’ve got to straighten your leg.” She was pushing harder and harder, like she wanted to hurt me, I couldn’t straighten my leg. I was ready to hit her. I said, “I’m small, you’re big, but I don’t feel good right now. You know what I’m saying?” I just turned over into a ball. “No more” I said. “I can’t take any more.” I was ready to bash the fucking bitch’s head against the TV screen. I told my porter, he said, “you get her name? You gotta get her name.” Missy says she couldn’t believe how nasty the woman was, adding, “doctors are supposed to be nice to you, to get you to do what they want.”

Rather than focus on whether the technician’s conduct was appropriate or necessary, what should be taken away from this encounter is Missy’s understanding of it—that it was painful and done in a manner that led her to feel as though there was maliciousness involved in the procedure, as well as Missy’s feeling that this was out of place, given that doctors (i.e., health professionals) try to get you to do what *they* want. Each of these suggests that the hospital setting is one in which Missy does not feel as though she has the ability to either set the agenda in terms of her own preference and desires, or control what happens to her body. Further, that Missy felt as
though the woman was *trying* to hurt her suggests an issue as to whether health care professionals reactions, which Missy can’t exert influence over, are part of the challenging dynamics.

After the incident, Missy confessed to me that she left the hospital with another patient to score—she said that she knew she shouldn’t have dope at the hospital, but after what had happened, she just needed to take the edge off. Having nurses then note that she was “off the ward” raises the suspicion of drug use and potential AMA’ing, one form of evidence for her inability to adhere to medical advice. It was indeed the case that she was leaving to score—but she did come back to the hospital and by her accounts it wasn’t strictly the score itself that was at work, the interaction with the technician being part of the series of events.

Aside from painful procedures, there are numerous other ways in which people substantially lack control within in medical settings, which influences their ability to carry on with participating in regimes of health. Missy would also become quite upset when she would have her disability cheques sent to the hospital, which meant that the money would be doled out to her, rather than her controlling her finances.

*Field Notes, February 21, 2008*

*Missy tells me that the hospital staff are holding $150 of hers and she’s not happy about having the cheques broken up into $25 amounts, twice a week. She says that “shit like that [happens] all the time, controlling people’s money.” Missy says that she understands that the staff mean well, but it’s not right, it’s her money, not theirs. “We’re going to do what we’re going to do, you know? So like now I owe people money for my stuff and I’m like, I’ve got it, I’ve got it, but [they have] it.” When I ask if she’s talked to somebody on the ward about it, she says that it wouldn’t be right, after all the staff have done for her, to go and bitch them out. “No way,” she says, “that’s not right.”*

One of Missy’s strategies in this sort of scenario would be to have me take her in a cab to the social assistance office on the day that cheques were issued—I would be waiting outside, so that she wouldn’t be tempted to do anything other than get the money and go back up to the hospital, but she would be in charge of the funds. All of this may seem, at first glance, to be irrelevant to
engaging in HIV care. But not being able to have control over one’s body or withdrawal that is experienced, not being able to manage pain because one is not listened to during the procedure, or lacking control because claims of pain and withdrawal are met with suspicion due to one’s reputation for drug use, reinforces the sense that one’s body is failing them. The knowledge that one is not able to do anything about this, because of the demands and regulations of the particular space, are especially troubling for many patients. The example also illustrates how carrying through on health care demands (e.g., remaining in hospital for extended periods of time) are not always straightforward for individuals whose social positions and identities dictate terms of interactions that are problematic for maintaining a sense of control and dignity.

In contrast to the hospital, women described themselves as having substantially more control on the street—being able to “hustle up” dope when they need it, knowing where and how to mobilize resources in informal street economies. While it is tempting to suggest that women are deceiving themselves regarding their ability to control their lives on the street, a knee-jerk false consciousness response needs to be questioned to some degree. Tina, for example, describes herself as a “good worker,” a view that is endorsed by a number of her health care providers who know how much money she can pull in, and how quickly she’s able to move a package of dope. When she’s got debts, it’s usually because whomever she’s working for has set her up to cash out short:

Workers are people who can sell dope fast. And they’re people who don’t fuck off. That’s what’s important. I’ve had people, bosses, that I haven’t known at all, but who come up and ask me to work. “Do you know who I am? I’ve seen you work…” But there’s a lot of people who will purposefully set you up so that you fail. That sucks. I’ve been in that situation a couple of times and it’s not easy to get out of. Especially when you’re out there and there’s nobody else to work for but that person. You know you’re…you know you’re going to fail from the get-go, but you want the dope and so you’re going to take the chance.

These are not the words of someone who is self-deceived. She knows there are risks with the undertaking, but with limited bosses to work for and her assessment of her skill, it’s a calculated
risk. Suggesting that women are self-deceived about their abilities to remain in control serves to quiet a dissenting view on non-adherence; it functions to smooth over the messiness that is day-to-day life and uncritically endorses aspects of the conventional view of the relationship between non-adherence and drug use, as well as the canonical view of drug users as individuals who fail to achieve the standards of rationality.\textsuperscript{15}

The juxtaposition between women’s abilities to maintain control and the requirements of much of the medical system is also how a community physician describes the challenges of remaining in hospital or clinical waiting room and carrying through with medical advice:

\emph{First of all, people are they’re on the move. They’ve got to keep moving around, they’ve got to do their deals, they’ve got lots of money to make and lots of substances to use and lots of connections that have to happen, so, they’re afraid and in control at the same time and they self-medicate, so they’re used to that level of control. And they’re very skilled, you know, you and I down here wouldn’t last a second. It’d be terrifying and we’d be terrible. So if we don’t be successful down here, why would they be successful with those sorts of skills in a place where you’re supposed to lie in bed, or sit, you’re not given your substances? You know, you’ve got all these anxieties about what’s happening to your stuff on the corner. And so and so owes me this and so and so I owe that, and you know, and here I am all of a sudden facing, I’m not running around, I’m facing boredom, you know, the reality of my failures, people telling me what to do. Um, you know, I’ve probably had that all my life, um, I’ve been abused, and beaten, been in jail, and all that stuff. Pretty difficult.}

Given the ways in which people are used to surviving and managing within their street environment, the conventional approaches to thinking about adherence to therapy fail to adequately address the ways in which the actions depicted by the medical system as rational may in fact be incommensurable with externalities that shape one’s life circumstances, or intolerable, with respect to one’s sense of integrity and control over oneself.

For many individuals, not only those who use drugs, having a sense of control over one’s body is a central aspect of one’s experience of health. I intend to come back to this point, given that it seems to reflect the normative view of selves as ideally having rational control over unruly corporeal experience. For now, it is worth exploring how antiretrovirals, although sometimes
serving as a reminder of illness and of transgression, do offer the promise of a potential source of control over a highly stigmatized and often visible condition, and at what price that control comes. There is an extensive literature examining metaphors of HIV and AIDS—the foreignness of the virus bolstering allopathic and military metaphors of invasions, battles, assaults, and defenses, rhetorically demonstrating the need for medications to slow what had been understood as an inevitable death sentence (Sontag 1988; Sherwin 2001; Patton 1990; Patton 2007).16 I take it that part of the appeal of the allopathic, militaristic images of the body as battleground, stealthy viruses hiding due to latent infection, and the assault from antiretrovirals, is the image of using medicine to exercise rational-technical forms of control over infection.

But the challenge here is that the control promised by ART comes through the expertise of physicians and virologists—those who supply the tools to win the battle and those who are able to measure whether the battle is being won. When there is dissent about appropriate treatment measures or protocols—be it with ARVs or methadone substitution—patients’ bodies also become battlegrounds for competing networks of medical authority. As Foucault describes, specific elaborations of knowledge (like drug mechanisms of action) are interconnected with instantiations of disciplinary power. In many ways, discipline also articulates with liberty in the spaces of clinical medicine and public health (Foucault 1973/1989, 36-39). Institutions such as the medical clinic are accepted as legitimate and normative; recommendations and prescriptions are endorsed by individuals along with allopathic practitioners as solutions to their respective health problems (Petrina 2008, 223-224; Turner 1997, xiii-xvi).

But for those who live in a community mired by representations of irresponsibility and incompetence, the voluntary, autonomous, and self-governing dreams of medical practice may come to play second fiddle to the disciplinary discourses. Being in control of one’s viral load requires a certain loss of control when one lives in a neighbourhood where it is presumed that it is best for ARVs to be linked to methadone and that one needs to be watched each time a pill (or
methadone) is ingested, to make sure it actually goes down the hatch. Perhaps this is the price of health. For those who live in environments where they have decidedly little control over important aspects of their lives (e.g., living in social housing or shelters, trying to survive on social assistance benefits, having work opportunities that mostly reside within the domain of illicit and informal economies, etc.), “health” may come with too high a price tag. Brushing these concerns aside, by invoking popular images and tropes of drug users, will simply not do. Nor will it suffice to fail to interrogate the self-governing aspects of medicine, on the presumption that those who do engage in technologies and technique of self-regulation with respect to their bodies and general health are now “stabilized” and closer to the presumed norm.

Depicting failures in the motivation to engage in HIV care as resulting from drug use alone, and generating interventions around that explanation, not only ignores the ways in which a rational actor model fails to account for the variety of reasons for drug use—it also ignores the challenges that are generated by the interventions themselves. Some women would, for example, want to be on methadone to help contend with their withdrawal symptoms when they weren’t consistently able to score. At other times, the ways in which methadone practices routinize and discipline patients’ lives to the health care system were too problematic for them to carry on with the programs. Methadone scripts are typically written for one week time periods, and ingestion is witnessed in a pharmacy. Fear of “diversion,” selling one’s methadone dose on the street, means that patients in the neighbourhood are not given take-home doses (carries) of methadone. It is also common practice to try and ensure that a patient sees the same methadone provider—a reasonable request, on the grounds that addiction treatment requires a good therapeutic relationship. Ideally, following through with these regulations and restrictions leads to the habituation of “stable” behaviour, adherence to ART, and victory over the virus. The liberatory and disciplinary elements of medical interventions are co-produced in methadone maintenance therapy, and women’s experiences in the program vary along these lines.
In settings such as the Downtown Eastside community clinics, physicians often work in sessional contracts, with a limited number of hours each week. Few appointment times are given out and it can be a challenge to get to the clinic at the right time, on the right day. Invoking the language of mental health disorders, methadone prescribers express concern that patients who have challenges making it to the clinic at the same time each day for their script are “splitting” the health care team or somehow trying to be manipulative; forgetting, sometimes, that their own work schedules are often less predictable than they imagine them to be.18

Philippe Bourgois’ work examining methadone substitution therapy as an exemplar of disciplinary techniques, located within academic, medical, and juridical fields that make up a knowledge/power nexus, is germane to these issues (Bourgois 2000, 168). So-called “stabilized” patients are those for whom methadone has become a technology of self-control and productivity, while eliminating the pursuit of illicit pleasure. This is the ideal situation within which ART is administered and adherence (apparently) facilitated.19 In San Francisco, for example, methadone programs are preferentially geared toward heroin users who are seen to be in need of careful monitoring (Bourgois 2000, 175). Amongst health care providers working in Vancouver’s inner city clinics, those whom I had contact with who self-identified as being on the more strict side with methadone (e.g., not wanting to continue prescribing methadone when a patient had serial urine screens showing opiates and other illicit substances) indicated to me that they would nevertheless be willing to continue to write a script, even if they were dubious of the benefits for a particular patient, if they were on ART. Whether or not it helps with adherence to therapy, methadone does act as another tether to the medical system. Where it is successful, one might wonder whether this has to do with having seasoned patients to daily care.

Being tied to the health care system, through daily dispense and methadone, is seen by some women as a barrier to adherence, rather than a facilitator. Having had HIV for a decade, Angel’s regimen is complicated by substantial resistance to antiretrovirals—she is currently on a
regimen that is often referred to as “salvage therapy,” requiring a combination of tablets, boosters and injections.\textsuperscript{20} She finds it frustrating, not only because the injections can be painful, but because she feels as though she can’t leave the Downtown Eastside neighbourhood—taking medications in front of her family in Northern British Columbia would be unacceptable and there are a number of complications in moving her methadone prescription. Feeling as though she just wants \textit{one day} off of it all, she doesn’t trust herself to follow through with the regimen on her own: when the interventions that were meant to promote adherence to therapy create conditions that make treatment difficult to partake in, such interventions \textit{generate} their own necessity.

\textit{I can’t go anywhere because I have to take it every day for the rest of my life. Same with the methadone. I can’t go anywhere without having that. Or pills. I can’t go anywhere without having it. I can’t go home. Like my family’s back up North and I can’t go there because of my pills…} (Angel)

Angel’s medication is \textit{for life} in two competing ways. She sees it as her lifeline, bringing her from a CD4 count of 10 to one of nearly 400, from “97 pounds, soaking wet” to what she felt to be a healthy 147— but the day-in, day-out of treatment is also in some ways a life sentence.\textsuperscript{21} In Angel’s case, she describes a positive relationship with the nurses who provide her medications on a daily basis—were this not the case, ingesting medicines would be far more onerous. The challenge to contend with, mostly ignored by academic and medical discourse concerning methadone and ART, is that this same disciplinary structure is (at times) a barrier to partaking in the health care system.

\textbf{II. PERSISTING WITH INTENTIONS: CHALLENGES WITH POVERTY AND ILLNESS AS FAILURE}

Carly was extremely articulate in describing how her limitations in adhering to ART were related to her challenges with what felt like relentless aspects of HIV care. Under a rational actor model, this challenge could easily be understood as having problems with persistence and follow-through. Much in the same way that a lack of readiness or motivation is depicted as relating to addiction, lack of follow-through is often attributed to on-going drug use. Having
critiqued the use of drug use as a heuristic within the analysis of non-adherence to ART, I hope that the reader’s critical antenna has been raised to this sort of explanation. Carly’s description of the challenges with the various aspects of care are decidedly more subtle than that suggested by a rational actor model:

“The biggest one for me is the blood tests, the counts and all that stuff. Keeping up with doctors appointments. You’ve got health issues all the time, you have to think about it. What you can catch. Just…trying to make the different appointments for the things that can affect your HIV. All the blood tests are the hardest thing to get through.

Anticipating. Waiting for blood tests. And when you first start on them [meds] it’s blood tests every month. Right now, it’s every two weeks. It’s hard to get through every day, knowing you’re really sick. (Carly)

The pills themselves were part and parcel with getting blood work done, as well as making it to the clinic for appointments (more often, standing in queue for half an hour to get a number that would then allow one to wait in the office for at least two more hours before actually seeing a physician). A major issue with adhering to medications and medical advice was the day in, day out, aspect of taking medicines, and more importantly, the expectations to monitor one’s health and take part in the health care system. With serious illness such as HIV/AIDS, the demands of bodily management, expressed by medical practitioners and generated through clinical guidelines and research, become deeply integrated with one’s actions in everyday life. But for individuals living in the inner city, HIV infection is one more aspect of one’s life that is ordered by health and social services. These issues are not reducible to competition of priorities, or preferences between drug use versus health services.

I have argued against the interpretation that Carly’s challenges with blood draws can be explained in terms of follow-through on her intentions, as conceived by a rational actor account of adherence. But her experience describes more than this—she articulates the challenges that relate to the widespread view that HIV-related illnesses are representative of personal failings. Carly’s description of anticipation, the wait to hear about whether her liver function tests or her
CD4 count and viral load are getting worse, was remarkably similar to her description of the anticipation and anxiousness in waiting to see if her HIV antibody test was positive. Given that viral load measures are taken as indicators of adherence, they, like the antibody test results, are felt by patients to be a kind of verdict.

Although population-level analyses and studies of non-adherence are not meant to blame an individual, adherence as well as morbidity and mortality are analyzed in terms of risk categories of HIV infection. And “risk” often references socially transgressive actions and racialized identity categories that are subsequently seen as dangerous. The putative carriers of HIV are defined against the “general population,” that is for all intents and purposes heterosexual, white, mentally competent, and non-drug using (Sontag 1988, Patton 1990). These same “variables” are used to define who is paradigmatically non-adherent; as the risk of non-adherence tracks along the lines of risk of HIV itself, one inscribes deviance and transgression upon the other. Having a body marked simultaneously by the pathology of HIV and of drug use doubly inscribes notions of transgression and deviance, as non-adherence to ART and medical care carries the same “normative shadow” as HIV infection.

Each clinic weigh-in demonstrating further weight loss (a reminder that one is wasting—from crack use, from crystal meth, from HIV), each set of medication side effects and new illnesses, the multiple visits to clinics for methadone, HIV and other general medical care, serve as a reminder that one is sick. Not only is this “heavy,” as Dee describes it, because of the possibility of death and dying—the reminders of illness are also construed, by women and sometimes by health care providers, as a personal failing because of their being connected to transgressive acts such as drug use.

*After a while I’m really really struggling with myself to keep it together. Like, I’m doing it, barely. Barely liking it. It’s barely enough to say now I’m deserving enough for this part. But then it was like the other part would come too fast and I’m like, ‘oh no! I forgot my pill.’ It’s like oh fuck, I didn’t even know the day changed because I’d been up all night. Now it’s like I fucked it up again. Or whatever. *(Dee)*
On the standard accounting of non-adherence to therapy, one might focus on Dee’s statement, “After a while I’m really really struggling,” which suggests challenges with persisting with care. Her further statement, “oh no, I forgot my pill…I didn’t even know the day changed because I’d been up all night,” might then be used to highlight the significance of memory, motivation, self-efficacy, or frequency of drug use on her struggles keeping up with therapy. But she’s been struggling after a while, which is to say that she’s moving back and forth between being “on top” of things and then barely keeping herself together—persistence is in fact there. But when she’s at a lower point, she doesn’t like the medications, nor does she feel that she deserves them. And then with the missed dose, she has “fucked it up” again. Persisting with treatment is more than a matter of becoming motivated and then maintaining follow-through; Dee’s experience emphasizes the significance of the continual threat of being outed as a failure. This is particularly profound, given the intensity of the engagement in the health care system that is required of her if she’s to be on ART.

Likewise, having to present oneself to clinic staff and iterate how the previous health care plan has yet to be implemented, regardless of how mutually agreeable it might have been at the time, is a reiteration of personal failing. Outreach workers would, for example, describe how having to explain oneself and these failures would increase anxiety around an upcoming appointment, leading to situations where women would make themselves unavailable as the appointment day drew near; women become elusive, altering their movements through the neighbourhood to avoid a run-in with their worker, thus avoiding potential recrimination; all the while reinforcing ideas of themselves (and drug users in general) as non-adherent.23

The sense of failure with on-going and progressing pathology doesn’t only relate to encounters with health care staff. Many of the women I spoke with felt that their illnesses would be understood as failings by their families, as well as by wider society. Human subjects are, as
critical theorists argue, cultural products. Subjectivity is a product of positioning (economical, rhetorical, etc.), ideologies, material constraints, and cultural conditions, all of which structure experience. Pejorative views of drug users, particularly as the no-good, non-productive, non-contributing leeches of society are inescapable. To have an infectious illness that requires expensive medications, and that is understood (rightly or wrongly) to be a result of drug use, layers illness with these negative figurations.24 In a number of different interviews, Missy describes herself as “fucked up,” internalizing the pejorative social connotations of drug addiction.

Fieldnotes, October 22, 2008

Missy tells me that she found out that she’s not going to get any more chemotherapy. “It’s my own fault,” she says. I ask her if she feels that we (myself, hospital staff) could have done more for her. She says no, “it was me. I wasn’t where I was supposed to be.” I ask her if the answer about chemo was never, or if it was not right now, based on your life circumstances. She says, “it was never, never, never again, you’re going to die. At least, that’s how I look at it.” I ask her if she wants me to talk to the staff about it, she says no, she should just accept that there will be no more chemo. When I follow up on the ward, a staff member says that the cancer agency will give her an appointment later in the month and if she makes it to that one, they’ll look at restarting chemotherapy. She tells me that Missy has gotten herself a reputation for taking off and the docs don’t want to deal with her.

The feeling that she is responsible for the situation compounds the weight of having a cancer diagnosis, especially given that this is combined with an unfinished treatment course and no confirmed remission. That Missy had gotten a “reputation” suggests that her sense of being at fault for the discontinuation of her treatment is shared to some extent by the ward physicians. This is particularly salient given the negative moral valence of drug use. When an interaction with the clinical staff is taken to be a “death sentence,” as Missy describes above, it is all the more challenging to carry on following through with other forms of medical advice, therapies, and interventions. On a rational actor view, drug users need to be cajoled into staying with treatment. But conditions for engagement in the health care system are given to patients by health care providers. Clinically, Missy’s health care providers felt that she could very well
finish her chemotherapy, but only if she would prove herself capable of abiding by the rules set out for her by her health care team.²⁵

This speaks to another contention that I will explore in the next section, that the immanence of suffering and death has a profound effect on an ability to participate in medical regimens. Missy resigned herself to not receiving more chemotherapy, to accept what was to her a fatal prognosis. Under those circumstances, what would be the point of “improving” her reputation on the ward by dramatically altering the ways that she knows how to survive—through illicit economies that put her in the midst of buying, using, and selling drugs, which the hospital staff take as antithetical to her health? But as I examine further on, the various institutional responses to drug use, the presumptions that are made regarding drug users’ abilities to adhere to medical advice, and the requirements that are given in order to participate in the daily regimes of allopathic, rational-technical medicine, mean that the imagistic and figurative construction of drug use and drug users can also intensify pathologies. In contrast to the rationale of biomedicine, it is not simply a matter of “choosing” health by refusing illicit substances. To follow an allopathic, biomedical perspective would be to ignore the way that daily survival generates tensions between appreciating and resenting care, the signification of illness amidst a context of generalized and sometimes overwhelming suffering, and the way that HIV-related illnesses are internalized as personal failures. In a twist of bitter irony, the challenges of being on ART while using heroin and crack end up continuing pathological processes, reinscribing a sense of failure when unable to follow through with medical advice, chemotherapy, or pill regimens.

Finally, Angel, a woman who receives her ARVs through an HIV home care program, described to me yet another aspect of adhering to therapy that I take as problematizing simplistic views of persistence within a rational actor model. While she appreciated the daily care her nurses provided, the benefits of having support with a complicated and often difficult medication
regimen, she also in some ways resented that care, for its intrusion on her life. After telling me that she wouldn’t be alive, were it not for the persistence and care of the nurses, she stated the difficulties with their persistence, which can be read as raising difficulties for her ability to follow-through on care:

Every day. Day after day after day. Some days I don’t want to have anything to do with it. But it has to be done…sometimes I feel like running away and hiding before the nurses get here. At times, I want to hide away and forget about the injections for a day. But no, you can’t do that. Because they tell you the next day, they will, they’ll be there the next day. They’ll be on your toes the next day about missing yesterday. Because they will come back. You can’t miss a day. (Angel)

Any kind of intervention or policy that is going to be successful will have to contend with the challenges of simultaneously appreciating and resenting care. Health care providers can’t, for instance, simply presume that because they pragmatically see what they are doing as both the rational and good thing to do for their patients’ health, their patients also share that view, and so should (or will) act accordingly.

III. TRUST IN EXPERTS, CONFIDENCE IN HEALING

The assumption that drug-using patients ought to have confidence in the goodness and rationality of the health care system is contradicted by the dynamics described in the previous sections. It is routine for those patients who are seen as members of a uniform group, label, or vice (drug users) to be denied the sort of control over their circumstances, due to the presumption that drug use is a marker of irrationality, irresponsibility, untreated mental illness, and is also a proxy for non-adherence. Given the conditions within which clinical care occurs, widely acknowledged by health care providers and patients, it is unsurprising that trust in the medical system is low. What I also want to claim is that such lack of trust is not unreasonable.

To be adherent to ART is in many ways to resign oneself to a relentlessness of contending with HIV infection in the face of likely continuation of suffering and serious illness. While it may be tempting to argue that if one really wants to live, he or she would willingly take
their medications and follow medical advice—this is far is too simplistic a proposition.

Presuming that people aren’t resigning themselves to daily care if they are being helped or made better by that care is suggestive of a “restitution narrative,” in which the illness is an interruption, something to be overcome in order to return to normal functioning (Frank 1995). In contrast to a restitution narrative, few women could tell me what they thought the future held for them, or understood their health in relation to the future. Some had hope that it would be better than their current conditions, but details were missing. As Tina put it,

A lot of people would say, ‘what do you see in your future?’ And in my future, I have, it’s blank. I don’t see any future, it’s just blank. I never…’what do you see in your future?’ Nothing. Does that mean that there is no future? Or does that mean that you know, I don’t get it.

Taking for granted that people will simply “see” that they need to take their medications to become well, and that this ought to motivate their behaviour, minimizes the profundity and experience of illness and presumes that individuals are universally able to live in the future; it minimizes an ever-present engagement with the imminence of death (Ezzy 2000, 606).

Mortality rates amongst women living in the Downtown Eastside and who inject drugs are reported to be dramatically higher than the overall population of women in British Columbia (Spittal et al. 2006). Serious illness, interpersonal violence, accidental overdoses, and suicides are part of the everyday experiences of the women that I followed. Even with the advent of triple therapy, HIV infection is still widely understood by community members as a death sentence. Likewise, a number of experienced HIV nurses refer to their work in the neighbourhood as “palliative” and suggest that this is a more appropriate model to follow in terms of care-giving. One of them would often say to me that there wasn’t really any getting better: “we’re just waiting for the next crisis.” Given the exceedingly high mortality rates and low life expectancy for community members, this isn’t a stretch.
It is possible that this obstacle to adherence is captured in conventional models, through measures relating to depressed mood or even self-esteem, but it’s not clear that mood scales are capturing its complexity. Likewise, while a rational actor model might make hay of the data, positing that not having a sense of one’s ends or future makes it difficult to understand and determine appropriate means to achieving those (thus the non-adherence), it is certainly not the case that such a model will appreciate the nuances of the situation. Nor will the model offer insights into the ways that health care providers ought to facilitate trust, if it is the case that a non-trusting attitude and lack of self-efficacy are seen as connected to personal pathology or drug use. Conventional approaches to thinking about adherence and affect will also likely be overly conservative in estimating the resiliency and agency of those who are unable to see a future for themselves, and will not account for what could be called an individual’s audacious sense of hope, given the community statistics.

IV. KNOWLEDGE AND UNDERSTANDING IN RATIONAL ACTION

Adequate information concerning the seriousness of one’s illness as well as the utility of the medications used to treat it—their functions, side effects, dosages, and timing—is a relatively uncontroversial aspect of adherence within what I have been calling the “conventional” view. This seems to be the case, even in light of the fact that studies often fail to demonstrate a correlation between compliance and improved knowledge regarding diagnosis and treatment (Hunt et al. 1989; Sacket et al. 1975). In contrast to the health-belief model, which suggests that patients will comply with physician’s orders when they believe an illness to have severe consequences and that medications can ameliorate those, a number of the women pointed out to me that having a serious illness and having to monitor oneself for further symptoms and indicators of progressing pathology were in fact hindrances to following advice.
Dee expresses the challenges of having to contend with the understanding that she was very sick, describing a period of time where she was heavily using and also largely non-adherent to therapy as digging herself into a hole:

_The way I was going down, I was digging myself a hole after a while, determined to die. These are other addicts going ‘wow you were crazy man. You were really crazy then. We didn’t see you living really long.’ No I guess I didn’t either, after a while. Like I said, I just dug myself a hole already and I was already in the hole and I couldn’t see out, already being sick and that. It was like I didn’t have a choice in the matter._

This hole, importantly, was one that she was already in, because of the fact of her illness, which she understood to be part of the longer, challenging trajectory of her life—adoption by a White family, a difficult reunion with her birth family, and having to give up her own son for adoption. Not seeing a way out _because_ of the illness also made it difficult to adhere. The knowledge of serious illness overlaps with what could be termed on a rational actor account as a lack of confidence. But her assessments of what the health care system is likely to achieve and her knowledge of illness contradict the conclusions that a rational actor model would produce.

It is important to consider that it had also been Dee who had described the relationship between feeling sick and taking her medication—_not_ knowing that she was very ill was also something she had identified as a barrier to adherence. This is an instance of the kind of tension that is significant in terms of understanding various aspects of adherence, but that is often left uninterpreted on conventional models of adherence. In a conventional account, the inconsistency might be boiled down to the following: drug users who are heavily using (as Dee was above) fail to take medications for a variety of reasons; those who don’t understand how sick they really are (as Dee’s previously described) have a hard time adhering. But this interpretation ignores what Dee is saying about the relationship between being really sick and taking drugs. Following both views closely, letting them stand _together_ in tension, provides a different insight, that there is a relationship between the endlessness and seriousness of illness and challenges with medication.
use, which drug use may sometimes overlap with, insofar as using drugs can become a coping
strategy for contending with illness and suffering. If we are to truly listen to her experience, it is
erroneous to ignore the tension between her two statements and conclude that drug use simply
leads to non-adherence.

Carly and Missy also described how difficult it was to get through each day, knowing that
they were sick. Missy once said to me,

*I think about it all the time. I look at that hospital bed [nodding toward the bed in her
room] and seriously, it’s what reminds me, every day. These days, I’m not feeling so bad
though. I’m taking the meds, that’s helping…*

Missy’s life circumstances are such that her private spaces are entwined with health services,
such that illness, even when she’s feeling a bit better, is ever-present. Again, there is a tension to
be explored: her medications are helping with the symptoms of HIV infection itself and allowing
her to feel better than she had previously, but they, along with the hospital bed and her
supportive housing unit, are reminders of illness. In a rational actor account, we might say that
her knowledge of her illness and her understanding of how the medications are helping are what
lead to adherence. But this fails to address how it was simultaneously challenging for her to
contend with an understanding of her illness and need for medications and health services.

Whether the medications are appreciated or not and whether the housing unit is taken to
be supportive versus an invasive reminder of illness depends to a great degree on what else is
going on in Missy’s life and how well the care regimen fits into that at any given time. When she
needs to be out on the street, coaching herself to just “keep it together,” a chest radiograph or
blood draw requisition are problematic in a way that they might not be during times that she’s
laying low from neighbourhood dealers whom she owes money to. If we want to claim that the
dynamics of drug use and dealing are challenges for sustaining adherence, it isn’t obvious that
this can be attributed to lack of knowledge or impairments of rational decision-making.
Thinking about the role of knowledge within a rational actor model on another level, ensuring adequate knowledge is also seen to relate to the engagement of individuals in their health. For individuals who are not socially and economically disadvantaged, this manifests in an ideal of “shared decision making” that is generally uncontested within the practice of medicine. Alan Cribb describes the move toward shared decision making models in health as a response to both paternalistic models of care and the tendency of so-called person-centered care to be (paradoxically) professionally-centered (Cribb 2005, 45). In the case of the latter, person-centered care appears to be simply a reminder for the professional to be responsive to the client; *professionals* facilitate the patient’s participation. In contrast, *shared* decision making has both parties involved in decisional processes, sharing information, building consensus and agreeing on the treatment to be implemented (Charles et al. 1997). Here is a rational actor model in full force: shared information generates adequate knowledge as well as motivation, enhancing the potential for persistence and follow-through, as well as improving interpersonal trust within the medical system. Although clearly these are idealizations, they are notable for the way in which they function as a gold standard of achievement for clinical interactions.

The shared decision making ideal is only minimally extended to those living in the Downtown Eastside, if at all. My earlier discussion of the ways in which patients with substance use issues would be described by clinical staff in the hospital and community settings as being like “big kids” is also significant to this point. A shared decision making model does not apply to children—paternalism is the accepted form of health interaction, with some consideration for how the child feels, if only for instrumental reasons. There is apparently little purpose or feasibility to collaborate or build consensus with patients who are seen as emotionally volatile and prone to rash decisions; patients who are described by staff in the language of developmental stunting. Given that children are paradigmatically taken to be non-rational and teenagers irresponsible, this imagery functions as a schema under which a drug-using patient’s actions will
be interpreted, i.e., whether or not a person’s lashing out or refusal to participate in health services was an instance of justifiable anger and an indication that some emphasis on consensus building would be both appropriate and effective.

Moreover, idealizations of HIV care directed toward drug users are tangential to those depicted by the shared decision making approach. Ideal ART administration for drug using patients consists of directly observed therapy (DOT) models and/or linking ARVs with methadone to establish a stable environment for these patients and ensure adherence. Patients may or may not be given a choice of how they will be observed and followed on their medications (DOT, pharmacy, or medications given daily by housing personnel in certain approved buildings), but it is taken as best practice that they are observed. It is rare for people in the Downtown Eastside community to have medications that are not delivered on either a weekly or daily basis, or not individually packaged in pop-out bubble packs that can be inspected by health care practitioners.

When she was on HIV meds, Carly was the only woman I had followed who picked up her medications once a month. She had adamantly refused to go back on the regimen unless she could do so. Carly was a rare exception, among the group of women I followed and amongst those who consume ARVs in the inner city. There is a limited extent to which dispensing methods are up for negotiation; more so when one has a reputation for previous instances of non-adherence. Similarly, there are general “no negotiation” policies posted in community clinics regarding the prescribing of certain drugs that are thought to have addictive potential and street value (e.g., valium, Tylenol 3, benzodiazepines); in hospital, discussions about methadone substitution or morphine administration are very often one-way, given that patients are not generally seen as credible with respect to reports of pain or withdrawal.27 Medical residents, students, and attending clinicians are reluctant to believe reports such as these from Downtown Eastside residents, due to the presumption that they are malingering in search of free narcotics.
Patients are well aware of these worries. In one interview with Tina, she had told me about the way in which hospital staff often don’t believe her accounts of pain or withdrawal, presuming her to be “drug seeking.” Likewise, while assisting with an afternoon women’s clinic one winter day, another woman described to me the pain she was having in her shoulder—she described it as “real” pain, reminding me more than once that she wasn’t “a junkie.” The difficulty is that when someone is, in general, presumed to be “drug seeking,” or amongst the category of people who are thought to do so, requests for additional pain or withdrawal therapies are met with suspicion. To put it mildly, testimony of individuals who are taken to be paradigmatically irrational or untrustworthy is generally not well received. Such individuals often lack standing to make claims based on widely shared (imaginative) conceptions of social identity, for example images that posit drug users as unreliable and deceptive. Hence, women’s concerns to deny the applicability of the junkie trope, or failing that, to attempt to assert that one’s pain or withdrawal symptoms are in fact “real.”

Discussing a phenomenon she calls epistemic injustice, Miranda Fricker (1998) describes how knowledge is enshrined in the figure of the “good informants,” those who are credible, rational authorities:

The position of powerlessness may place one under general suspicion of being motivated to deceive, in a way which the position of powerfulness does not. Further, powerlessness diminishes one’s ability to protest one’s trustworthiness—especially if it would be at the expense of the reputation of someone more powerful…Things may be especially complicated if the knowledge that we seek is about contested social phenomena…it may be that if she attempts to convey her perception of [the interactions], she will find she lacks what Lorraine Code has suggestively named the ‘rhetorical space’ that her answer requires. (Fricker 1998, 170)

Fricker emphasizes how norms of credibility are often conferred on a basis of access to various dimensions of social power. Both internal criteria for rationality authority (competence, trustworthiness) and external indicator properties of credibility continue to operate within the domain of the privileged, a temporal extension of the way that scientific activities and empirical
study were once strictly within the domain of gentlemanly pursuits (ibid, 171). Presumptions of credibility, competence, and trustworthiness—presumptions underwriting rational authority—are distributed differentially according to the ascribed identities of speakers and interpreters (Code, 1995). As I discuss in Chapter Five, drug users, through conventional imagery applied to the grouping, are held in opposition to norms of rational agency. There is substantial data suggesting that physicians are reluctant to treat pain in patients with problematic substance use (Cohen 1980; Merrill et al., 2002; Savage 1996). It is my contention that this relates in part to commonplace views of drug users as being morally suspect and lacking competent cognitive faculties—that is, views that drug users are failing to meet the standards of rational moral agency.

Recalling how drug users are depicted as “childish,” we can see how the infantilizing language and imagery commonly applied to the category serves to diminish credibility and rational authority, given that children are not thought to be able to achieve the standards of autonomous rational agency. As feminists have persuasively argued, historical representations of femininity have been linked to child-like behaviour—frivolous, silly, head-in-clouds—so as to depict women as oppositional to the “man of reason” (Code 1991). Using the language of childishness in clinical settings similarly diminishes the ability of those depicted by such imagery to make claims and demands against others who are held as paradigms of reason. Medical expertise and professional standing exacerbates the epistemic hierarchy that already exists on the basis of contrary images of rationality between drug using patients and health care providers. Physicians and other health care professionals have the advantage of being deemed trustworthy experts—experts who hold the keys to the narcotics cabinet. In light of my critique of rational actor models, it is important to emphasize that it may be the case that epistemic injustice and the lack of credibility and standing (attributed on the basis of social identity) only makes it appear as though drug users have failures in knowledge and understanding that lead to
non-adherence. What contribution epistemic injustice itself has in leading to non-adherence, is left off the table.

INSTITUTIONAL MIMESE AND THE DYNAMICS OF CONTROL

Is it surprising that prisons resemble factories, schools, barracks, hospitals, which resemble prisons? (Foucault 1975, trans. 1977)

Much of my discussion thus far has focused on internalized and interpersonal aspects of adherence that are unaccounted for in the conventional methods of study. Conventional approaches to thinking about adherence, which I have argued to be founded on a model of action that views agents as rational actors, function according to the standards of traditional scientific practices, in which the knower (subject) is distanced from objects upon which its generic gaze settles, pulling what Haraway calls the “god trick,” seeing everything from nowhere (Haraway 1988, 582). Akin to the way in which a rational actor model muffles those voices and experiences that generate tensions in need of interpretation, experiential forms of knowledge production are not part of the conventional views of adherence, given that they are too obviously situated, subjective, and not subject to statistical analysis.30

In contrast to this, I have tried (rhetorically, at least) to write myself into my discussion of research methodology. Allaine Cerwonka describes the body of the researcher is a “landscape” for analytical insight; citing Diane Nelson, Cerwonka argues that attention to the physical experience is important for drawing attention to the material and cultural particularities of knowledge production, “messing up” the clean, unified categories that are so easily invoked within transcendental Western epistemology (ibid, 35). Paying attention to the significance of the researcher’s affect and lived experience is not meant to be a throw back to romantic intuitionism (Cerwonka 2007, 36). It is also not to say that visceral responses, affect and the “feel” of a situation are to be taken as a given or as a naturalized form of truth generation. Instead, it recognizes that responses to research situations can be employed as analytic prompts,
just as an interesting or unusual pattern of potential biomarkers might be, in a clinically-oriented study.

In the fall of 2008 Missy was sentenced to two months in prison for trafficking and possession. It was through a strange sense of déjà vu when visiting Missy that I came to consider whether the institutional “feel” of hospitals and clinics, which shared a number of intangible similarities with the correctional facility I had gone to, might relate to non-adherence to medical advice and medical care. In hospital I had certainly heard people refer to the place as “jail” and the nurses as “wardens” or by military-type titles. For some time these seemed like mere colloquialisms. But as Missy and I sat across from each other, separated by a pane of bulletproof glass and talking through a phone receiver, it seemed as though we might have been sitting next to one another in the hospital—the countertops in the visits room were so alike the countertops that run underneath the windows in the hospital rooms where we had spent much of our time together; the same kind of countertop that I would lean up against at the nursing station when trying to find which room she was in this time.

I thought about the previous day, when I had tried to come for my initial visit. My bus to the prison had been running behind schedule and I was turned away for being “late.” I was five minutes early for my appointment, but was required to be there fifteen minutes early, and the guards had already let everyone into the visiting booths. Trying to get a message to Missy about the appointment timing was like pulling teeth. Each time I asked the guard behind the bulletproof glass in the front room if I could do something (e.g. send a message, get a pen), my requests were met with a sharp “no.” After a moment of silence, I would be corrected on what was the appropriate action to take. No messages to prisoners. But you may write a letter. Letters must be in an envelope. No, we don’t have envelopes; no you can’t make one. Envelopes must have a return address. Envelopes can’t be sealed. On and on it went, until
finally I could hand over a “letter” explaining to Missy that I wasn’t allowed into the appointment, but I’d make another one for the next day.

The bulletproof glass, the guards, the endless bureaucracy—these might just as easily describe a number of community clinics in the Downtown Eastside. As aspects of formal institutions (medicine, prison), they shape how it is possible to move through a space, interact with other individuals in it, and achieve some sort of end—they function as disciplinary techniques. When operations run smoothly there is, for the most part, no obvious orchestration of power: the panes of glass, the presence of a guard, various one-way swinging gates or controlled entrances and exits in both environments shape how bodies move in space. Discipline is productive in both environments as well—well-behaved patients who take their queue number and sit quietly are able to stay in the clinic, thus they receive their methadone script or praise for good blood test results, while prisoners who keep their head down and do their work get the $1.50 per day. Those who complain loudly are treated as “difficult,” and a dynamic develops whereby greater external control is placed upon patients in order to have them conform to health care providers’ or guards’ expectations regarding behaviour. Systematic hierarchies are instituted in both environments: in medicine, paternalism directed to those who are not deemed rationally autonomous and thus incapable of shared decision making; in prison, actions strictly controlled by guards and wardens.

The “feel” for the similarities of the institutions acted as a prompt for further exploration of what their significance might be for adherence to ART and to medical advice. Asking Missy about what it was like to be in jail, she replied:

*M:* Being jail? Ugh. They put you in there to think about what you did wrong, for sure. And it was like, maximum. So, it’s boring. There’s nothing to do. It’s the same thing every day. The same thing. You get to go out in the yard, everyday for an hour. That’s pretty much all you got to look forward to. And coming out? I don’t know. I was scared.

*I:* What was scary about it?
M: Just that...I don’t know. Freedom I guess. It’s scary. [pause] Freedom is scary.

What is striking about this conversation is that Missy’s choice of descriptors for jail mirror challenges listed by a community physician with respect to staying in the hospital. The physician, quoted above, had said that one of the problems was how people are facing boredom, facing the reality of their failures. As Missy described to me, jail was boring, it meant sitting around, thinking about “what you did wrong.” I followed up on this issue with a physician whose research has focused on women in prisons. She stated:

*I think, the way you’re treated, the stigma, the way that you’re not really able to make your own decisions. And it happens in both locations. You know, in hospitals you have, not only the stigma, but the paternalistic, “this is what you need,” and then when you’re in the jail, you lack huge amounts of power, feeling out of control…and in both places you have…you aren’t able to openly use or admit that you’re using, and again, it pushes any drug use totally under the table, which means its going to be risky manner. At the hospital you can, depending on how sick you are, you can take your own discharge, but then you get yourself the reputation for you know [leaving], and there’s…it may have been easy to treat, but then there’s problem further on.*

She also mused that detox may be a similar experience—strict rules, limited control, and a refusal of the service the only way out of disciplinary procedures. As she rightly identifies, the obvious difference between medical services and prison is that one does have the option of self-discharge in the former. Indeed, this may make all the difference in the world. But then consequences arise—a reputation, as well as worse health outcomes.

For Missy, there was another layer of similarity between being in jail and being in hospital, insofar as there was something frightening about leaving the confines of each institution. On the day before she was to be discharged to a new room in a government housing building, after her longest stay in hospital, she disappeared. Staff were upset that she left AMA, because of all their efforts getting housing arranged and making follow-up appointments, and so on. But she hadn’t actually left the hospital, reappearing a day or so later. She had been hiding out on the fourth floor balcony, terrified of leaving what had become her home over those few
months. Sheepishly, she told me that she was just being “a big baby” and that she was frightened of going back out. As with leaving jail, going back out into the community means falling into old relationships, old habits, and ways of making ends meet—back to the dealing and hustling.

Missy’s being frightened of leaving hospital or jail seems to be at odds with my discussion of the ability (and desire) to self-discharge; this may be so. As I have tried to emphasize, the inconsistencies and contradictions are important sources of information that are all too often lost in the processing of quantitative studies, which have a tendency to smooth over inconsistencies by relying on stereotypes and prototypes, brushing away that which does not conform to the canonical, controlled experience of experts in the field. Understanding what is significant to women’s being able to be adherent to therapy means contending with these tensions. The fear of leaving both institutions came when Missy was being released on the say-so of the institutions’ representatives—“kicked out” of hospital, as she would sometimes say. In contrast, leaving AMA is an issue of attempting to exert control over a situation that one feels is intolerable because of a lack of control, whether over pain, finances, or withdrawal. In both instances, a lack of control is an underlying factor. What seems like an inconsistency may not be such.32

CONCLUDING REMARKS: PARTIAL PERSPECTIVES ON ADHERENCE

Methods, their rules, and even more methods’ practices, not only describe but also help to produce the reality that they understand (Law 2004, 5)

Unlike statistical “truths,” which present themselves as knowledge production of the “S knows that P” variety—universal, generic, and informative of an inert world—the body of knowledge I have been attempting to construct over the course of this chapter is positioned and partial. The work conjoins the perspectives of various actors within the field of HIV/AIDS care in the inner city—women, who are patients; physicians, nurses, researchers who examine, treat and study them; myself, in following and studying each of them. Their experiences, along with
my own, are embodied; the data I present are mediated by myself and those who interpreted along with me. And whereas the supposedly transcendent positioning of generic knowers justifies the data cleaning processes in other forms of investigation—one is removing “noise,” rather than evidence—the apparent contradictory views presented in this chapter are all taken as significant to the understanding of adherence to ART.

My scrutiny of rational actor models at the start of the chapter might potentially account for both of Dee’s contradictory articulations: that it was hard to remember to take pills when she didn’t feel sick, and that it was hard to follow through with care when she was so sick. But it does so by legitimizing one aspect of experience (not feeling sick often means lack of motivation, which appropriate information from health care providers can correct), while undermining the latter experience (positing that the relationship between being very sick and non-adherent is solely a result of drug use). Thus on the conventional accounts, norms of rationality are seamlessly interwoven and a singular story produced, rather than allowing the contradictory experiences to destabilize the conventional view of adherence. That there is no one knower doing the integrating, that the experiences are understood in relation to a presumed universal, is a problematic feature of adherence that conventional accounts share with quantitative (statistical) research practices. The seamless story that hinges on understandings of rationality also provides the impetus for solutions and interventions on the part of those deemed to have epistemic authority on the issue of adherence—medical practitioners and biomedical researchers.

Rather than dichotomize adhering to medicines and daily care as either willingly and actively engaging in services that are appreciated and seen as essential to one’s survival, or finding them to be an imposition and a reminder of the limited control one has over one’s future, I have been raising these issues in an effort to conceptualize the dynamic tensions that play out in the acceptance of HIV care. We are left, however, with an additional puzzle: if indeed the
phenomena of “adherence” and the category “drug users” are much more diverse than they appear and useful information can be gained by attending to this diversity, why is it that they are represented as singular and that the data cleaning continues on in earnest? The everyday experiences of women also mark the start of my exploration of the idea that the assignment of certain groupings and categories within research methods and in clinical practices are not merely descriptive—they play a role in the production of the realities they seek to investigate. We define first and then we see.\textsuperscript{33} The singular representations of categories and labels carry on insofar as they are productive of their descriptions. This is the onset of my answer to the second question I posed at the start of this project: what are the effects of continuing to employ conventional measures surrounding adherence to ART? In the chapter that follows, I offer a more systematic consideration of the role that the self-as-rational-agent has in medical encounters, its figurative content tapping into commonplace beliefs concerning who is and who is not a credible, rational authority. These images help to create and sustain the reality that its model seeks to investigate.
CHAPTER FIVE
LOOPING EFFECTS AND THE CONSTRUCTION OF NON-ADHERENCE

Conventional views of adherence to ART tacitly suggest that the relationship between adherence and rational action is universal, unsituated, and timeless. Objectivist models claim authority on the basis of a transcendental epistemic position. The work that produces the conventional picture of adherence, in which the tensions and inconsistencies are smoothed over, stay behind-the-scenes, never admitting that even this knowledge is part of lived experience. But all researchers are socially and politically situated, and implementing survey questionnaires or extracting data from a database are likewise situated—they take place in particular locations and at given points in time (Malkki 2007, 198). And as feminist and post-colonial theorists of knowledge have articulated, certain forms of experience and certain knowers are situated in positions of privilege, offering what is taken to be evidence rather than anecdote. Testimony and experience are not rejected across the board (Code 2006, 51). In this chapter, I continue to examine implications of objectivism within HIV/AIDS research and clinical practice, looking specifically to a view of how the underlying norms of universality, rationality, objectivity and authority shape women’s experiences in the medical system.

In the previous chapter, I argued that various forms of adherence (to antiretroviral therapy and to medical advice) are premised on models of rational action. I suggest here that conventional approaches to studying adherence also support an idealized view of a “self-as-rational-agent,” against which the figure of a non-adherent individual (particularly a drug user) is depicted in contrastive terms.¹ Images of drug users as failing to achieve rational agency (therefore failing to adhere to therapy) contribute to the wider conditions that shape what actions take place within clinical settings. Because a rational actor framework also makes it appear as though group membership is an immutable characteristic of a particular kind of person, its
application in medicine contributes to a milieu in which the conditions leading to non-adherence and pathology in HIV care are replicated.

In order to appreciate this looping relationship between classifications of non-adherent individuals and the conditions that lead to non-adherence we need to grasp what it is that underwrites the legitimacy and credibility of a rational actor model and the idea self-as-rational-agent in this discourse. Interestingly, “adherence” became a topic of research interest when various studies of cardiovascular medications suggested that more than thirty percent (in some reports, up to fifty percent) of hypertension patients were non-adherent to therapy. Non-adherence to all manner of medication regimens is consistently understood to be common, particularly with long-term, chronic conditions (Cheevers 2005; Becker and Maiman 1975, 10; Chesney 2000, 1600). And yet unlike research and clinical practices surrounding HIV/AIDS, there is little suggestion that middle-aged (often, middle class) men constitute a particularly homogenous group; nor is there a suggestion that as agents, their non-adherence reveals an underlying irrationality or irresponsibility that requires social and medical forms of policing, either for the sake of mitigating escalating health expenditures or for the sake of their health.

When the issue is the treatment of hypertension, non-adherence is, if not unremarkable, at least to be expected. The dissimilarity between the two forms of non-adherence is striking: there is an acceptance of a certain level of non-adherence within cardiovascular disease management (evidenced within the clinical research literature) and a push within the chronic care model of health to modes of decision-making that are more genuinely shared between physicians and patients. On the other hand, much of the HIV/AIDS adherence literature and numerous care providers presume that drug users will be non-adherent if not carefully monitored or closely guided by health professionals. Strong-handed interventions in the name of both individual and public health are therefore legitimized as “best practice” by those who develop care guidelines. Additionally, in the setting of HIV/AIDS care, non-adherence is construed as dangerous. For all
of the efforts within conventional approaches to HIV/AIDS research to evaluate and critique stigma associated with HIV/AIDS and its treatment, the issue of blame and the depiction of non-adherence as recalcitrance is far more significant in HIV/AIDS than for other illnesses.

The issue of blame and recalcitrance with non-adherence to ART surely has to do with widespread images and figurations of those seen to be most at risk of infection—drug users, commercial sex trade workers, migrant workers, non-white, non-western others—imagery that is pejorative and discriminatory. Here, I will focus predominantly on the figurations of drug users, while also taking time to discuss the overlap with images of Aboriginal persons and women more generally. The imagery I have in mind depicts drug users as alien to wider epistemic and moral communities and sets them in opposition to images of ideal agency projected by medical science and technology. Importantly, figurations of drug users are also set against a view of medical enterprise as objective, rational, and working in the service to humankind. And as I shall demonstrate, such evaluative judgments impact patients within health care encounters, altering ways in which health care interactions proceed once such judgments are part of the clinical environment. This is particularly profound for those who live in environments that are much maligned, notorious spaces; likewise for those whose ascribed identities and ethnic groups face similar figurations and depictions of immorality and irrationality. Thus, I suggest that the imagistic burden of the non-ideal agent is even greater for Aboriginal women who use drugs.

My concern is echoed by Leslie Robertson, who describes Aboriginal women in the Downtown Eastside community as having to “carry the racialization of substance abuse” (Robertson 2007, 534). This is especially pertinent given that images of western biomedicine and scientific enterprise, which are taken as authoritative on matters of adherence and HIV-related statistical research, are arguably within the domain of white male privilege.

The oppositional relationship, between the ideal self-as-rational-agent and drug users as deviant kinds, has a tendency to exacerbate problems within clinical interactions, reinforcing the
very same conditions and outcomes that are investigated using such idealizations. In this
chapter, I employ this oppositional relationship as a way to offer a different interpretation of the
statistics that suggest that particular categories of individuals (drug using women, Aboriginal
persons) have greater challenges with adherence and worse clinical outcomes. My purpose here
is not to deny that a relationship exists between taking ARVs, CD4 count, and the typical
pathologies related to HIV/AIDS—rather, I aim to examine the role that the categorization itself
plays in this relationship.

IMAGES AND OPPOSITIONS IN THE ASCRIPTION OF IDENTITY

Field Notes: January 16, 2009

Tina and I are sitting on the metal steps of the fire escape of her building, with our backs to the
going-on of the alley. It’s cold out, but it isn’t raining. There was already a piece of cardboard
on the step where we decided to plunk down, so we sit there, huddled from the wind. We’ve been
talking about how she came to be living in the Downtown Eastside, after running away from her
adoptive family as a young teenager and being set up to hustle by a boyfriend. She pauses from
the story to take a toke from the piece of rock she will eventually smoke over the course of the
afternoon. The smoke has a bitter, chemical smell to it as it wafts past me.

When I ask Tina about what happened the last time she was in hospital she says that people there
treat you like dirt, “because you’re a junkie.” She says that they don’t believe you, that you’re
in pain, or that you’re in withdrawal. She says that even though she wouldn’t wish the kind of
pain she has on her worst enemy, she does wish they [the hospital staff] could feel what it was
like, “even just for thirty minutes.” She says they wouldn’t be able to handle it, but then they’d
know what it was like. I ask her what she would say to people at the hospital, to tell them about
it. She corrects me, saying that it’s not the kind of pain you can describe, that you have to
experience it. She says that she’s never been so dope sick as the last time she was in hospital,
when they didn’t give her anything for her opiate dependency – “no morphine, no methadone, no
nothing.” Her home care nurses made it up to the ward on the weekend and stayed there with
her until the methadone was straightened out. She says that they’re the only reason she was able
to stick it out, after two days straight of vomiting, sweats, shakes and diarrhea. She was ready to
take off, because of the withdrawal and the pain. But, she tells me, it’s a good thing she didn’t.
She wound up being in there for three weeks.

She names off other times that she feels like she’s treated like a piece of dirt, worthless. The
police push her around when she’s living on the street, they’ll force her to move from location to
location; they rifle through her things, throwing it all in the dumpster. She has to climb in and
get it out, after they’ve left. She says that it’s not much better at the shelter, they spray you down
down for bugs and expect that you’ll be trying to get “clean,” encouraging you to think about going
into detox. “But what if you’re not ready for that?” she asks me. She tells me that living in a
shelter is worse than the street, “it’s degrading. They don’t treat you like you’re a human.
You’re a piece of shit to them.” I ask her if she feels that it’s even harder for her, being Native.
She doesn’t think so. “No, it’s just the drugs.” When we get up to leave from our perch on the wrought iron staircase that sits above the alley, it takes her a few minutes to go down the half-dozen steps. Her hip has locked up. She says that people don’t understand how difficult it is for her to get around, and the pain she’s in, especially in the mornings. They think she can just run around all over the place because she’s got to be in the alley, dealing. She says, “it’s so hard for me.”

My time with Tina on that January afternoon brings to the forefront of this chapter some of the ways in which drug users are seen as transgressing ideals of the self-as-rational-agent. Moreover, the field note excerpt emphasizes the effects that an ascription of the categorization “drug user” has on women’s interactions within the health care system. Significantly, the quality of health care interactions may, at times, replicate more obviously problematic encounters with other forms of authority. For Tina, being classified as a drug user translates into troubled interpersonal interactions regarding pain medication and methadone maintenance therapy within the hospital setting. With both outright declarations that one’s pain is not taken seriously, as well as with less explicitly confrontational encounters, Tina described to me how she, as a drug user, feels as though she is seen as an individual who is not trustworthy, lacks dignity, and has little to offer society.

Tina describes how she experiences interactions within various institutions and with their representative agents as being suffused with stigmatizing and judgmental social attitudes toward substance users in the community, even when actions and policies carried out by the institutions in question are reasonable from the institutional viewpoint (e.g. ensuring that one does not enter a shelter with bed bugs, scabies or lice). Having to be checked and sprayed for bugs or having to collect her belongings from the dumpster reinforce her sense that others see her as lacking dignity and trustworthiness. It will not suffice to suggest that the underlying justifiability for such actions from the perspective of the institution or organization can overcome such problematic elements of health care and social services delivery. Nor will it suffice, in attempting to determine adequate treatment protocols or social service policies, to chalk up such
experiential elements of health and social service delivery to a person being overly sensitive or “difficult” about institutional guidelines, while presuming that institutional representatives are bastions of rationality and reasonableness. It is this very opposition between the images of medicine and medical practitioners-as-rational and drug using women-as-difficult that I aim to critique in the remaining pages of this chapter, having already begun to critically depart from liberal humanist views of rational autonomous agency and the rational self that I laid out in Chapter Two. Below, I discuss ways in which women in the community are envisioned to oppose an ideal self—the morally and epistemically autonomous, rational, responsible agent given by the liberal tradition. This account of the self is one I have linked to the notion of a generic detached knower, which operates within conventional methods of studying adherence and much of the medical practices surrounding HIV treatment and care. It is also this view of the self that is taken as the norm from which demographic categories relating to non-adherence deviate.

I. CHAOTIC

In comparison to idealizations of pill-takers who are adherent to therapy, images of drug users overlap with those of mental illness; both groups contravene images of rational agency. Drug users, whether adherent or not, are frequently depicted within HIV research as “chaotic” (Elliott 2007, 87). For instance, one study reports, “high reported rates of unstable housing, income assistance, and low education levels among [participants] reflect the chaotic lifestyle patterns of this population” while another states, “the risky behaviours and high rates of seroconversion were believed to be inextricably linked to the chaotic, needle-sharing behaviour of the cocaine binger (Shannon et al. 2005; Spittal et al., 2002, my emphasis added). The image of chaos is also employed within health care encounters—numerous physicians, nurses, medical residents and medical student interns use the word “chaotic” to describe both patients themselves as well as what are viewed to be their “lifestyle choices.”
Colloquially, *chaotic* is meant to depict unpredictability and lack of order. As a signifier for those who are mentally ill as well as those who are drug using, *chaotic* depicts the Downtown Eastside neighbourhood itself, as the community is thought to be made up entirely of these *kinds* of people. During an interview, for instance, a nurse with experience in both community and home-based care described to me a female patient who was unable to stay in hospital to complete antibiotic treatment because of challenges with drug use, saying, "*she can’t stand staying there very long, she can’t tolerate that, because of her chaotic lifestyle and her addictions issues.*“ Similarly, her instructions on how best to contend with providing care to drug-using patients in the neighbourhood were explained to me in the following way:

*They don’t want to talk to you? Fine. Don’t push it. It might take months before you’re able to go into that room and have a decent conversation with somebody...But just being a continued presence in someone’s, a chaotic person’s chaotic life, it you know, has an effect...*

In contrast to the stability that the health care provider sees herself providing, this chaotic patient is unstable, with respect to her external life as well as inner mental life.

The descriptor, *chaotic*, is decidedly contrary to the image of an agent who goes about integrating competing desires and beliefs so as to rationally carry out a life plan that is in accordance to those values. The term functions much in the same way that Diana Meyers has described for other culturally normative descriptors—complex imperatives concerning behaviour and psychology are condensed into an emotionally compelling figuration, which serve to perpetuate a particular world-view (Meyers 1994, 52). In this instance, imperatives and cultural taboos against drug use and euphoria (one might refer to this as euphorophobia) and norms of rational agency are embedded in the term, enabling views of the self-as-rational-agent to operate as a fundamental organizing principle. Even if we want to reject typical philosophical views of agents as dull plodders and hyper-rationalists, being chaotic may also be in contrast with those agents who “go with the flow.” Amongst agents who do not carefully calculate their life plans,
there is still a general presumption that *qua* agents, they rely on instrumental reason, exercising agentic skills that allow them to keep familiar values, traits and desires in view (Meyers 2005, 48).

*Chaos* has deeper signification when it is applied to *female* drug users—insofar as the term also suggests emotional disquiet, anxiousness, or restlessness, the application of the term *chaotic* calls upon imagery of the body as uncontrollable and unpredictable, as well as immanent, rather than detached or neutral. Femaleness has long been associated with what is left behind by the light of Reason (Lloyd 1993, 42). Moreover, women’s bodies are taken (metaphorically and, sometimes, literally) to be leaky or fluid, lacking “proper” borders between inner/outer, self/other, mind/body (Shildrick 1997, 17). This is the very same imagery that has been held as evidence for women’s natural lack of capacity for rational agency. Inasmuch as *chaos* contrasts with solidity, rationality and neutrality, it serves as an inferior referent within the dualist mind-body construction, a construction that places drug-using woman even further from ideals of rationality.

Margrit Shildrick, in a discussion of the relationship between depictions of *chaos* and the functioning and imaginary of post-Enlightenment scientific thought, emphasizes the cogency of this last point. Describing the hierarchical structure of the opposition between male-culture and female-nature, Shildrick writes:

The more positively valued aspects of nurturance were overridden by the rationalist characterization of nature as wild and chaotic, but nevertheless fundamentally machine-like and potentially controllable…Losing control of oneself is to a large degree synonymous with losing control of, or having no control over, one’s body. In scientific and medical discourse in particular, it is quintessentially a feminine rather than masculine trait, predictable and tolerated in women, but sufficient to disqualify us from the mental self-governance necessary to (rational) moral agency. (Shildrick 1997, 26-27)

Further to this, traditional philosophical theory is also described as having assumed it to be the case that women, racialized minorities, and people with disabilities are incapable of acting independent of the body and are thus incapable of rational agency and “rationality” more
generally (Meynell 2009, 5). My purpose in pointing this out is not to claim that women drug users are deemed more chaotic than men—this would require substantial comparative data. What is relevant, however, is that notions of chaos, when applied to women in the community, can more easily gain a foothold on the imagination, because of the historical understanding of irrationality as feminine trait. Insofar as racialized others have also been subjected to figurations of irrationality, the parallel argument might be made that the imagery of chaos attaches itself more readily to drug users with Aboriginal ancestry. Reasoning, integration, continuity and agentic skills are denied to “chaotic” drug-using women, ever more strongly for Aboriginal women; this need not be a conscious or explicit application of the trope of chaos to function in such a manner.

This specific aspect of the imagery used to conceptualize drug users is indeed an issue of tropes and stereotyping, and not a neutral descriptor. We can grasp this by examining the paradoxical ways in which so-called “chaotic” individuals have rather predictable, patterned, mundane daily lives, just as so many of us do. It is not simply the case that “chaotic” is a benign description, agreed upon by those who work with the community and its members. Tina was able to remain on her methadone and her ARVs during her numerous periods of homelessness because her home care nurses would generally know where to find her—which alley or park she’d been sleeping in recently, which section of which street was her turf when she was dealing. When that was to change, either she or her partner would call to let the nurses know where to find her. Tina described to me that she didn’t really mind the routine of the medications: seeing the nurses was one of the best parts of her day and she looked forward to it.

Missy would often say to me as we were parting ways and deciding when to get together again, “you know where to find me.” And it was mostly true—she had areas that she could regularly be found at and friends nearby who knew where she had gone if she wasn’t on the section of the block that I had expected to find her at. Carly, on the other hand, would often be
described by health care providers as “running around the streets,” phrasing meant to indicate that she was in the midst of wheeling, dealing, and hustling (all instances of chaotic behaviour). Much like the way that Tina and Missy’s rather mundane, predictable schedules belie their “chaotic” behaviour, Carly’s running around was predominantly back and forth between her room in the supported housing unit she lived in and the clinic she attended five blocks up the street—for medical care, lunches, breakfast, social assistance cheques (administered three times each week), methadone scripts and doses, and for food bank donations. More often than not the multiple clinic trips had to do with being given numerous appointment times for different medical concerns and procedures, due to conflicting scheduling (e.g. her methadone prescriber not being in when they were expected by the administrative staff to be in clinic) and visits that were limited to one or two concerns, due to time constraints. Very often, determinations of drug users as chaotic ignores much of the way that the complexities of bureaucracies, poverty, and ill health become incorporated into the everyday experience of individuals, making their movements back and forth within the community seem entirely related to drug use and transgressive behaviour.

II. GETTING A REPUTATION

During Missy’s first admission to hospital in 2008 for a diagnosis of HIV-related cancer, there had been a push by hospital staff to keep her in hospital for the duration of her chemotherapy. Prior to that, she had been living in one of the alley doorways. To discharge her to a shelter with the expectation that she would present herself to the cancer agency across town, in order to continue chemotherapy, was deemed unrealistic. But after a number of self-discharges from hospital and subsequent re-admissions related to recurring cellulitis as well as complications from the cancer, Missy was no longer going to be receiving chemotherapy. She was now described by one staff person as now having an “edge” that hadn’t been there when she was first admitted. It was noted that she sometimes responded to staff with eye rolls and snide
remarks. I was also told that she was developing “a reputation” with the physicians on the ward, such that one staff member remarked to me that she was surprised each time she came back from a weekend, to see that Missy was still in hospital. As the number of hospital admissions grew, it came to be that when the matter of discharge and follow up care was raised during rounds, few physicians were willing to advocate for her to remain in hospital to complete whatever the current therapeutic regimen was, as it was thought to be likely that she would leave hospital again. What would be the point of trying to keep her treatment continuing, if she would just going to leave anyway?

Over the eleven months that she moved in and out of hospital and clinical environments, Missy had become, in the eyes of her health care providers, “chaotic.” Having developed a reputation with ward staff for using while in hospital, for leaving against medical advice, and not following through with therapy in the community, she was treated as deviant or transgressive. She transgressed not only norms of politeness and those against illicit substance use, but insofar as she was non-adherent, she was seen as transgressing norms of rational agency. The fact that her non-adherence was attributed to drug use reinforced this view of her lacking rational capacity. I found the notion of Missy as having a reputation noteworthy. It meant, to my mind, that the nurses and physicians, both in hospital and in the community, had memories of her—their encounters with her and their interpretations of her behaviour at any given point in time were referenced to her past, either through their own personal experience or through the historical record that the medical chart provided. Each self-discharge, for example, would result in a notation in the chart as well as (in most cases) a discharge summary sent to her community health contacts. Thus, she became “known” as someone who AMA’s. Transgressing norms of rationality, insofar as rationality is defined as following through with medical advice, is written into the language of her reputation.11
First, the idea of a “reputation” speaks to the significance within medicine of the view that the self is a thing that exists over time. Moreover, as I argue shortly, reputations are an element of health care interactions that exist in relation to conventions and standards of rational agency. In the philosophical literature, the emphasis on continuity and the integration of one’s memories over time is related to the processes of unification; we saw this with the discussion of traumatic memories and the undoing of one’s sense of identity. While this does capture something significant, it only deals with one small piece of this relationship between identity and memory. By emphasizing one’s own memories, these views inadvertently equate selfhood and identity with one’s personal (rather than social) experience. To be sure, trauma is frequently perpetuated by others and thus indicates how others can affect one’s sense of self, but on most accounts of trauma and memory, the impact on identity over time comes from oneself.12

However, as the notion of reputation suggests, others’ memories are also significant and may attribute identity over time, whether that identity is apt or desired. Naomi Scheman describes this evocatively:

Insufficiently noted by philosophical theorists of personal identity is the role of the memory of others in constituting selfhood. It is not just that we are the persons we remember ourselves being: We are equally, for better or worse, the persons others remember us being. The others around us may be loving or arrogant, thoughtful or careless, with their memories of us; and we can be grateful or resentful or both for being held in their memories, for being continuous with the persons they remember us being. (Scheman 1997, 125-126)

Although she doesn’t explicitly discuss memory, Cheshire Calhoun makes a similar point in considering the role of social conditions on integration. It is a mark of privilege, Calhoun writes, that one’s self-interpretation receives substantial social confirmation (Calhoun 1995, 241). Similarly, Scheman argues that the seamless integration process is a reflection of a particularly privileged self. One way in which social confirmation takes place is by the memories that others have of us. Privilege, on Scheman’s account, includes the ability to navigate one’s life world
without these messy aspects of the self that one has “forgotten,” in conjunction with others’ compliant memories:

The coherent remembered narrative, shared with others who hold us in mind, is an artifact of privilege in terms of both what it contains and what it omits…What we have are culturally specific narratives, which facilitate the smooth telling of some lives and straitjacket, distort or fracture others. (Scheman 1997, 126)

Scheman specifically argues that the messy, problematic aspects of the integrated self (those aspects that sit in opposition to rationality, for example) are split off and projected onto less privileged others.

By having a reputation as someone who AMA’s, whose drug use is rendering her life increasingly “chaotic,” Missy was implicitly (and at times, explicitly) held against an ideal agent who was rational as well as responsible; an ideal agent would be adherent to care, remain in hospital and act graciously toward staff. As her reputation became increasingly calcified by subsequent identifications of her as non-adherent, health care providers were less willing to give her the benefit of the doubt with respect to her intentions for following through on health care, translating, in some instances, into having fewer supports offered to her. It also seemed to me that with each hospital departure, the next admission would be fraught with greater challenges with respect to accessing timely services for pain and withdrawal management. I took this to indicate that being seen in ways that were contrary to responsibility and rationality made her less trustworthy, both morally and epistemically. Drug-using inner city residents are often referred to as the “frequent fliers” of the emergency department and hospital wards, and are presumed to come to hospital in search of narcotics. Clinical staff are unlikely to believe someone’s reports of pain or withdrawal when that person is “known” to have left as soon as they could get out of bed on the last visit.
III. HUSTLING

In conjunction with the view of drug users as chaotic or childish, which opposes them to the standards of rational agency, those who are drug using are seen as being untrustworthy and disreputable. The view of drug users as morally blemished doesn’t only relate to an abstract relationship between rationality and responsibility; drug users are explicitly referred to as “hustlers,” a term that imports a view of them as comparable to con artists. One home care nurse explained to me that some of his colleagues would get very upset by requests from patients for cigarettes, juice boxes, and food (which other nurses would sometimes provide using discretional funds) because they felt like they were being “hustled.” Likewise, concerns of health care providers on the ward and in clinics regarding whether an assertion of pain is duplicitous, stem from a concern about being deceived or hustled into providing narcotics inappropriately. In comparison, the term “hustle” when used by community members generally refers to their engaging in work within an illicit economy—drug dealing or sex work—or it would be used simply to depict the acquisition of drugs. Missy, for instance, felt that methadone would be helpful for her, so that she wouldn’t have to wake up and “hustle” first thing in the morning.

Two issues are of interest, with respect to hustling imagery and its function in opposing identities of drug users to those of ideal agents. First, many of the women that I followed would use items like cigarettes to gauge the attitudes of health care providers and to broker issues such as trust through these small tokens. Tina described to me that when she first met the two nurses who would become her primary home care nurses, she had no interest in thinking about being on antiretrovirals, but that she appreciated how they would always ask her how she was doing and offer her a cigarette when they came to provide home care services for her street dad, whom she lived with. Tina identified their regularity and their offer of a cigarette, regardless of whether she was willing to talk to them or follow up with health care, as a major component of establishing a relationship in which she knew she could count on them. Similarly, Dee talked
about how it was similar actions by a nurse in the community that brokered the connection that kept her engaged in HIV care:

Well I think it was the fact that she didn’t care what I was doing as much as making sure that, ah, she stayed in touch with me. I don’t know many people that would come in the bar to find me. I know the bar was downstairs [in lobby of the SRO], but still. And obviously I, I didn’t mind telling her I was going to be there. Basically she was the one I opened my eyes to when I was sick. I didn’t even see my parents there. I really couldn’t believe that she took the time out after hours to take me, to [get] herself to be there [at the hospital] when I woke up. I’d get cigarettes, and you know, things that nurses don’t do...

It was by going beyond the usual nursing job description—visiting her in the hospital, as you might a friend, going out of the way to provide necessary medications, offering cigarettes—that established trust and credibility. In Dee’s experience, the nurse was no longer an authority, setting the parameters of the encounter according to the case management rulebook. The interpretation of requests for juice, cigarettes, or ensure as hustling misses trust brokering aspects of health care interactions, relying instead on depreciatory imagery attached to stereotypes of drug users.

Second, being able to “hustle” quickly and effectively was often a source of pride for women especially, as it meant economic prowess and status that is not often attributed to women in the community. This is about more than being able to make money, having “fast hands,”15 or having drugs at one’s disposal—hustling is a form of work and being good at it often engenders respect. A good worker makes money and doesn’t beg off on their debts. Contrary to popular imagery of hustling as being manipulative and a mark of irresponsibility, hustling was described to me by people working in the drug dealing economy in honourific terms, just as one might if they were carrying out at any other form of work. I do not explicate these issues to represent dealing as a “voluntary triumphalist decision” (Bourgois 1996, 115). It is also the case that most of the women I knew who worked as dealers did, at some point, try and rip off customers or other dealers; Tina told me, “I’m no angel.” My purpose, in emphasizing alternate meanings
attached to hustling-related actions (high value symbolic token, trust brokering, entrepreneurial skill), is to demonstrate that alternate versions of “hustling” do not neutralize its negative moral connotations. Irrespective of whether or not a person who “hustles” sees their actions as positive, or doesn’t understand a particular action to be an instance of hustling, an image of a drug user as a hustler still sits in opposition to norms of reliability, trustworthiness, and credibility.

IV. TRAUMA, GENDER VIOLENCE AND VICTIMHOOD

As I have briefly touched on in the opening chapter, women who reside in the inner city neighbourhood are often described in the research literature and by health care providers as victims of violence and sufferers of trauma. Many individuals in the neighbourhood, women particularly, have had decidedly painful life experiences that include exposure to violence, including intimate partner violence and abuse within the foster care system and Canada’s residential school system. While there is a degree to which addressing such issues and their impact on health is appropriately politicizing health research, there is a problematic tendency toward linking the effects of trauma and violence with individual cognitive function, whether explicitly or implicitly. If we recall how “trauma” is a paradigmatic example of how a self might fail at achieving standards of rational agency (e.g. through lack of integration and unification), it is plain to see that there is a danger in overstating the significance of gendered violence data, or interpreting such findings in light of cognitive function. The images of overwhelming victimization and personality disorder related to trauma is another set of images applied to women in the community, which set them against the ideals of rational agency. Equating women’s experiences in the street with victimization determines for them a helpless, choiceless, and passive subject-position.

Despite the fact that it is acknowledged that women’s involvement in drug-use economies are often entrepreneurial and highly successful in terms of generating money and turning over
large quantities of illicit substances, non-agentic “victim” imagery persists. This is precisely the power of a large and interlocking set of images. Explaining the persistence of continued negative stereotypes applied to socially excluded groups, Diana Meyers writes that it is not uncommon for an array of discriminatory or pejorative images related to a marginalized group to conflict with one another—internally contradictory images continue to reinforce honorific stereotypes of dominant group members because the refutation of one image of an excluded group is taken as proof of another (Meyers 1994, 55). Women in the inner city fail to achieve rational agency when they are depicted as traumatized, but those who refute the victim trope fail as rational agents on the grounds that their involvement in drug economies confirms the presence of wanton irresponsibility and cognitive dysfunction due to the seemingly chosen “lifestyle” of drug dealing and consumption.

OVERLAPPING IMAGES

By opposing imagery of rational, autonomous agency, tropes of drug users and sex workers, along with identifiers such as IDU and FSW, are able to suffice to account for a breadth of reasons for non-adherence to ART and to medical advice, and limit the extent to which individuals so-grouped are seen as credible. Patients, viewed as health consumers, are made to bear responsibility for their lives and their health (Fraser and Valentine 2008, 59). Drug users decidedly do not fit the model of rational, activated, self-governing consumer-citizens (60). In many ways, recovery and methadone programs are meant to habituate these sorts of qualities, but of course, one’s drug using past is omnipresent, particularly in the form of others’ memories. When those memories are inscribed on medical charts and reinforced as “reputations,” it can be exceedingly difficult to break free of the imagery associated with the IDU category.

Although I have focused a great deal on images related to drug use, and to some extent on those related to the feminine, it is critical to identify that these are only two layers of imaging and figuration that operate in this setting. I was surprised to hear Tina say that she didn’t feel
that being Native made a difference to how she was identified and treated within the health care system, and hospital in particular, given the breadth and depth of stereotypical images and negative figurations related to Aboriginal people in Canada. I wondered whether my being White made such a question difficult to answer, or whether in her experience, the impact of being identified as a drug user overwhelmed the role that the imagistic figurations of Aboriginal women play in ascribing non-adherence to particular women. Poverty, social transgression in the form of drug use, as well as racialized and gendered groupings collide within figurative understandings of women who are using drugs and contending with HIV/AIDS. This is particularly true for Aboriginal women.

The images I have described gain deeper significance by being situated within Canada’s colonial history. In describing the impact of colonization on Aboriginal health in British Columbia, Mary-Ellen Kelm writes of the trope of the Indian outlaw who merges into the bush to evade capture, part of the fantasies of contact that extend to concerns about infectious contagions crossing racial lines in cross-cultural communities (Kelm 1998, 16). Being elusive to the law offers an image of Aboriginal people as not adhering to “community” (i.e. imperial) moral standards and failing to live up to ideals of responsibility. The intersection between images of the irresponsibility and marginality of Aboriginal persons and that of drug users is of particular significance.

Field notes January 8, 2009

I’m downtown, near the corner where Missy usually deals. We were going to meet up, but I don’t see her there. My phone starts to buzz—it’s an administrator from a supported housing unit, she’s trying to find Missy as well. A referral has been put in to have Missy move into the unit of the building that has medical support and the woman is wondering if I’ve seen her. She tells me that she understands that Missy isn’t exactly “against” receiving health services, but that she’s “elusive.” The woman on the other end of the phone tells me that it’s her understanding that Missy becomes more compliant when she’s unwell. She has a checklist of questions for Missy, to process the referral, so I tell her that I’ll pass on the number when I see Missy next.
Thinking about Mary-Ellen Kelm’s discussion of the trope of the Indian outlaw, I felt it was not insignificant that Missy was described as “elusive” rather than outright recalcitrant—not unruly, but also not docile. Elusive is interesting because it also denotes a sort of presence or physicality that is not apparent when one speaks of women as being “invisible” in the community. To be invisible in the community is to not matter—but women’s bodies do matter, as the highly publicized worries about community viral load, hospital utilization rates, and health and social service expenditures attest. Interventions in the name of health have been historically justified by images of bodies that are slippery, elusive, evasive, and by that, dangerous. Aboriginal women continue to be seen as needing to be “engaged” and brought into the health care system so that they are no longer elusive; no longer non-adherent and a potential contributor to community viral load or a risk to the public’s health. But to what extent does the health care system recognize its role in perpetuating their elusiveness? Historically, imperialism has invoked morality as well physicality in determining the need for a colonial pastoral power. Where HIV “risk” serves as a secular form of venereal sin, morality and health continue to be imaginatively linked and paternalism continually justified; all the more so when “risk” is connected to images of non-white, non-male, non-rational Others.

APPLICATION ERROR AND IDEAL THEORY

I have been concerned to demonstrate that depictions of health-related action captured by a rational actor model, along with “the self” given to us from the traditional philosophical account of the self-as-rational-agent, are not simply straightforward descriptions of what agents are like or how they get around in the world. Chapter Four problematized rational actor models, which underpin conventional explanations of adherence as a health behavior, on the grounds that the models fail to capture salient aspects of non-adherence to ART and rely on the uncritical adoption of liberal norms of rationality. In a parallel fashion, this chapter has critiqued a rationalist account of the self, on the grounds that certain categorizations of people are depicted
as grossly contravening the ideals of this account—the figurative content of the categorization “drug user,” for example, taps into commonplace, often discriminatory beliefs concerning who is and who is not a credible, rational authority.

It is worth pausing here to consider a counterargument frequently made by proponents of ideal theory, as it applies to my analysis thus far: they argue that we can make legitimate projections of features such as rationality, even if we believe it the case that people are not fully rational. There are, I think, two slightly different ways of understanding this thought as a criticism of my approach. The first is to say that simply because a model fails to explain every phenomenon or accurately classify all forms of action, is no challenge to that model, so long as it is useful in other (significant) domains. This way of conceptualizing the thought is expressed by Kwame Anthony Appiah in his discussion of the usefulness of thinking of persons as fully rational, even when it is the case that we recognize the falsity of this generalization. Appiah applies this discussion to debate between agency and structure, writing that an idealization such as rationality is a falsehood that is useful for some purpose (as in understanding agency). Since we are only able to work with the best possible theories we come up with at that given place and time, it may not matter that an idealization is not the best theory for some other set of interests or purposes, if it in fact works well for the purposes we intend for it.

Describing idealizations as useful draws attention to the fact that an idealization is meant to be for a specific end. Or, as expressed by Appiah, we might say that treating people as if they are rational actors works, depending on what it is about action or rational behaviour that we are interested in (Appiah 2005, 56-57). If we are interested in reasons for action (versus, say, causes of action), our interests may very well necessitate a view of agents as rational actors. This thought is akin to a distinction between an objection from principle versus one from practice. I may have in-practice concerns regarding a rational actor model in one narrow domain, but if this model otherwise functions usefully within a different domain, or for a different set of purposes,
this does not amount to an objection in-principle, given that there are other practices for which the models function very nicely. 19

A different (but related) counterargument would be to suggest that even if my critique is granted—that a rational actor model or self-as-rational-agent account generates a body of problems in the area of HIV/AIDS care—the theories are too important for the smooth functioning of a liberal democracy to be let go of. Call this the “counterargument from fear.” 20 Here, we might say that people ought to be treated as rational agents, even if it is the case that ideals of rationality are problematic for a select group, because doing so serves a much more important systemic function. To put it differently, even if there are issues in practice, it is the case that there are good reasons to hold onto the theory or model in principle. In politics, the view of the self I have critiqued might limit the intrusion of government bodies in what are rightfully private affairs, on the grounds that people are the best judges of their own interests; in medicine, this counterargument is taken as the basis for rejecting strong paternalism.

These counterarguments are each fine points but as I will argue over the remainder of the chapter, they do not undercut my analysis. In the two sections that follow, I argue that idealizations such as the self-as-rational-agent and rational actor model have an exclusionary or oppositional function when operationalized within research and clinical practice. Such idealizations shore up the borders between groups, while simultaneously serving to provide the content of those groupings, thereby perpetuating privileging (epistemic, social, economic) of certain groups at the expense of individuals imagined to be non-ideal others, whose marginal social positions are thereby maintained. Here is one reason to suggest that the problems I have been describing with respect to adherence and categorizations of drug users are not benign consequences of a model that is adequate for some other set of purposes. What is argued to be its systemic utility, or importance “in general,” is only possible at the expense of those who are excluded from its standards.
Moreover, these exclusionary identities perpetuate various pathologies that confer group membership to particular individuals. I take it that the two arms of my response will address the challenges identified above. First, I argue that the consequences of the model are emphatically malign; second, my response is decidedly as “in-principle” as it is “in-practice.” Additionally, I hope that it will become clear how principles are practices are in fact interlocking. Here then will be the remainder of the reply to the second question I posed at the outset of this work: what are the effects of continuing to employ conventional measures of access and adherence?

OPPOSITIONAL LOGIC AND SOCIAL IDENTITY

What does it mean to say that the model of the self-as-rational-agent has an exclusionary function when it is operationalized, or that social identities of drug users are oppositional to the self-as-rational-agent? To understand these claims, we first need to think about how views of self and collective identities are fitted into binary categories. These categories have an oppositional relationship insofar as the content of one position in the binary implies the negation of the other and the component parts are ranked in a hierarchical order—one position, as an unargued norm, is positive and neutral, while the other is held in reference to it, deviating from it. As de Beauvoir and many following her have argued, woman is understood as relative, that which is not-man. The same logic applies to heterosexist binaries, in which the lesbian and gay collective identities are held as the negation of the supposedly neutral (and natural) heterosexual norm.21 And the lists go on—feminist and disability theorists have developed extremely robust analyses of the implications of relational terms such as these, arguing that such binaries function to repress difference and exclude those who do not meet the normative standards set by a specifically able-bodied masculine White western capitalist ideal (Weir 1996; Shildrick 1999; Wylie et al. 2009). The good/bad opposition is a result of the dichotomy generated by having a supposedly neutral and universally accessible norm contrasted against a category marked by difference (Young 1987, 544).
The oppositional terms are also set in relation to other binaries, bringing hierarchical relationships to bear upon one another—rational/irrational is argued by Luce Irigaray, for example, to be part of sexed binaries, informed by its phallocentric logic (Irigaray 1985). The conceptualizations of drug users as failing to achieve the standards of rational agency, and the images and figurations used to depict this failing, relate this social identity to particular negations within binary categories. Women who are non-adherent and drug users, depicted as chaotic and irrational, bear the weight of ascribed identities that are constructed in opposition to that of a stable, masculine vision of rational agency as it is deployed within biomedical frameworks.

Being seen as not-rational through imagery like that of “chaotic” links the categorization to various other denigrated positions within a binary logic—chaotic links to the irrational, to nature, and the need for a pastoral power, such as one would receive from paternalist policy related to methadone prescribing and interventions such as directly observed therapy. Corresponding representations, for instance that of nature as chaotic and wild, requiring rational mastery over its dominion, imagistically reinforce the validity of the logic (Shildrick 1997; Code 2006). And as I have argued, this is more profoundly problematic for Aboriginal people: ethnic and cultural identities rest on the denigrated side of the binary; whiteness is taken to be the unargued norm.

One might wonder, of course, whether “drug user” is really a collective identity akin to lesbian, gay or Black identity. While it may frequently be the case that other social identities are more widely granted by the vast majority of group members and more frequently mobilized as part of struggles for political solidarity, there are nevertheless a number of shared features that I take to be paradigmatic of social identity. Take the issue of grouping and its relationship to identity—social identities are based on categorization of individuals. Clearly, “drug user” (likewise, IDU) is a “social” category. Societies make designations about what counts as an illicit drug and also concerning what criteria determine whether one’s substance use counts as an addiction, that is, problematic substance use. Methadone is a medicine that is used to treat
drug addiction, the distinction between methadone and heroin being that of moral designation—one licit, the other illicit; one generating productivity, the other pleasure (Bourgois 2000, 167). Antiretrovirals are medications—if one takes them felicitously, one is adherent; crack is a drug—those who smoke it are unlikely to be seen as adherent to their medications. To be part of the group, IDU, is to take part (or be presumed to take part) in the practice of injecting substances socially defined as illicit and be classified as so doing. Group membership is therefore intimately connected to a wider set of social understandings concerning the practices under question—some of those understandings relate to the personal identities of those who fall into the group or category.

My arguments in the previous chapters highlighted that there is an easy slippage between being ascribed membership to a group and thereby having a social identity based on that ascription—that is, being seen as a particular kind. While more familiar examples of grouping and identity are related to self-classification and self-identification with the images of group members, one need not mobilize around an identity (nor even agree with the grouping) to have the social identity category influence one’s actions or self-conception. Carly, for example, would vocally protest being treated as a drug user by health care workers, thereby rejecting the categorization. But she would also describe how she understood herself to be separate from straight (non-drug using) people, calling them “normal,” and contrasting herself with them. Various images and criteria within public discourse can ascribe identities to a given individual based on the grouping, such that individuals are recognized or understood to be a member of a particular group, even if the category is not entirely apt (Appiah 2005, 66-67). This holds, even if the actual group is fluid and its boundaries porous, due to the imprecision of the classification practices.

Social identity, both for standard collective identities and for drug users, often invokes a kind of essentialism based on ascribed group membership. An oppositional relationship imports
a view that the opposing “Other” is an other, unified within difference and seen as a timeless essence. In discussing social kinds, Sally Haslanger suggests that shared meanings and ideologies (e.g. of what “race” is, or what constitutes a “woman”) can interfere with our understanding of classificatory processes, such that we fail to see our own role in creating such divisions (Haslanger 2006). Even if it is widely agreed that drug users do not constitute a natural grouping, the division is nevertheless taken to be purely descriptive, and the role that classification itself plays in social identity formation is obscured. Here now we have the philosophical tools to dissect what is going on when epidemiological categories serve to produce immutable “kinds.” The logic of self/other totalizes both positions. Combining epidemiological categorization with cultural images and meanings attached to the identities of group members results in the members being taken as a kind of person. The unification that is generated by the oppositional relationship imports the essentialist or timeless features, which can often result in the naturalization of the binary.

EXCLUSION AND REPRESSION IN IDENTITY

Referring to identity as exclusionary is meant to indicate the normative implications of oppositional binaries such as man/woman, healthy/ill, or rational/irrational. In an extremely thorough discussion of relational and poststructuralist feminist analysis of self-identity, Allison Weir describes this exclusion as a “sacrificial logic.” Historical formulations of binaries such as man/woman, culture/nature, etc., have been tied up with the construction of Woman as excluded Other, and with the repression of difference (Weir 1996, 3). This sacrificial logic is argued by many feminists to apply, not only to gender identity, but also more broadly to self-identity; thus any identity is taken to be repressive of difference.24 The unitary self that is implied by liberal ideals of individual identity, particularly those of universal autonomous rights-bearers, represses the multiple, fragmented and conflicting aspects of the self that are common experiences, particularly for those who are not in positions of privilege. The exclusionary function is an
outcome of the oppositional relationship: every signifier carries a trace of its oppositional other. For each A, there is the trace of not-A, which must be marginalized or expelled (though not altogether erased).

Importantly, the exclusionary process that takes place within an oppositional relation polices the boundaries of the centre-margin relationship. Within the context of adherence to ART, the notion of a universal, unmediated, gender-neutral agent, imbued with rationality, functions as an exclusionary ideal inasmuch as the creation of this ideal is possible only by the expulsion of those who are its negation—namely, those who are understood to be drug using and non-adherent to therapy. Failure to achieve normative standards of identity, in this instance, pathologizes the drug using self as traumatized and fragmented, or as irrational and chaotic; such individuals are understood to be in need of paternalistic interventions. In all of this, there is a failure to appreciate how a purportedly rational self given by the standards of biomedicine is implicated in the construction of non-adherent behaviours.25

To grasp the extent of the harms generated by the self-as-rational-agent and health behaviour accounts of adherence founded on a rational actor model, we need to understand (1) how marginal social positions are maintained by the depictions of non-adherent patients as oppositional to rational actors and (2) how the pathologies and health consequences of non-adherence are perpetuated by this idealized view of the self. I have taken a number of stabs at the first contention, that the oppositional relation of identities maintains or polices the boundaries of marginal social positioning. Discursive formations (e.g. medical texts, epidemiological surveillance data) and face-to-face encounters are informed modes of conduct, assumptions, expectations, and normative meanings surrounding reason, responsibility and autonomy; constructs that function to exclude those who are not understood to fulfill the requirements of these idealizations. By virtue of their oppositional exclusionary functions, categories such as “drug user,” “non-adherent,” or “Aboriginal” are not merely descriptive or demographic. They
pit marginal or disadvantaged groups against the putative centre—the sober, healthy, rational agent.

In my earlier discussion of the self, I followed Naomi Scheman and Cheshire Calhoun in critiquing the conventional account of how memory is relevant to the self, on the grounds that traditional philosophical view focuses on one’s own memories and fails to consider how others’ memories shape self-identity. Scheman and Calhoun bring this criticism into the logic of identity dialogue, describing how those who face systemic forms of disadvantage often have negative and non-ideal aspects of identity projected onto them by privileged selves. Protestations regarding this are met with a lack of social confirmation of their worldview. In HIV/AIDS care, we might see this as the tendency of health care providers to mistakenly attribute what are ultimately background conditions that increase the likelihood of non-adherence to therapy (often, background conditions that health care providers themselves help to create) to facts about the patient, in relation to their social identity as a drug user.

There is a presumption of straightforwardness in medical practices, which, along with the presumed objectivity of the medical professional (much like the objectivity of the researcher) and their clinical and specialist expertise, place the actions of health care professionals beyond reproach. Health care providers need not examine how their own actions make it challenging to function in medical settings, nor do they need to address presumptions they might have about a patient’s actions, when those actions reinforce stereotypical views of drug users. The sense of surveillance that both Missy and Carly detested while on the hospital ward is a case-in-point. Missy, describing a typical encounter in which she would be accused of using drugs when she left the ward, said to me, “The one nurse, she straight up said, ‘are you going down there to use drugs?’ and I wanted to say, ‘why, do you want some?’ It just makes me want to keep my head down, not look them in the face.” Keeping her head down has as much to do with being presumed guilty as it does with the desire to remain below the radar of the nursing staff.
Missy would be particularly upset when she would leave to get food because the hospital meal wasn’t very appealing; other patients would argue that they wouldn’t need to go out to the balcony to score if their methadone wasn’t reduced or put into split doses. Presumptions of drug use escalate tensions, sometimes leading to an angry departure against medical advice and worsening health outcomes. Those departures would be inscribed in the medical notes and referred to at the next admission to the ward such that the patient would be known as prone to AMA’ing and physicians and nurses would adjust their behaviour and expectations of outcome accordingly. Even well-intentioned interventions and policies on the hospital wards and in community clinics, when they reinforce a patient’s sense of personal failing, lack of control, the relentlessness of medicine in one’s everyday life, will generate a milieu that makes it increasingly difficult for women to carry on with health care services, or “play the game,” as Missy would sometimes say. The role that health professionals play in generating this dynamic is only rarely acknowledged amongst professionals.

As I have previously argued, the epistemic authority of health care providers contrasts with that of patients who are understood to be drug users, sex workers, and the urban poor, resulting in reports of pain and other health care requests or demands interpreted with a view to the patients’ lack of epistemic authority, due to their categorization as a drug user. This limits the extent to which women’s own experiences surrounding adherence are taken up, as well as the extent to which they are seen to be truthful or reliable when it comes to adhering to therapy.

Patients’ lack of authority, connected to the positioning of their social identities as oppositional to norms of rationality, is part and parcel with a widely shared sense that expertise and correctness about the way that clinical care should take place is part of the epistemic domain of health care practitioners. As one home care nurse described to me, patients who were seen by staff as “difficult” were less likely to have either their health-related requests or their challenges to health care providers’ way of approaching care registered as legitimate:
Issues of both moral and epistemic credibility, desert, and authority are interrelated with one another and these issues help to structure the field within which patient decisions around medication ingestion and health care engagement take place. This last thought brings me to the second contention I proposed would serve as an argument against the view that the self-as-rational-agent and rational actor models were benign and perhaps would remain useful idealizations in principle. Namely, that the pathologies and health consequences of non-adherence are perpetuated by the oppositional positioning of drug users and rational agents.

DO YOU BELIEVE IN REALITY?
CONSTRUCTING CATEGORIES AND PREDICTING OUTCOMES

In Chapter Two, I discussed the issue of constructed identities as *kinds*, employing the work of Ian Hacking in order to suggest that being a member of an identifiable kind both requires and generates actions around the grouping, including things like statistical analyses, international policies and political organization. The actions and events that are mobilized around the category further inscribe identities of those so classified, by adding to the content of their life experience and altering the lenses through which those experiences will be understood. Aligning myself with Sally Haslanger’s critique of Hacking’s view of object construction, I argued against the insistence on cognitive and self-reflexive activities in determining how interactive kinds get off the ground.

If we are interested in understanding how looping effects function even when it is the case that the social identity of the grouping is ascribed by others and not straightforwardly internalized, we need to consider how the effects of networks of privilege and the production of knowledge are part of lived experience, and how group membership is affiliated with these. With respect to women’s experiences in the health care system, having a social identity that
opposes the paradigms of rationality (often embodied as health care providers) structures what actions and decisions are both possible and palatable. For example, the identification and subsequent treatment of a woman as a drug user may lead, under certain circumstances, to her withdrawing from health care services. Particular patterns of pathology are generated by this action. When the action is attributed to the women’s social identity, rather than the conditions of care, the strength of the grouping and its association with particular health outcomes is bolstered. Patterns of pathology are subsequently employed as visible identity markers of the group.

Take cellulitis, a common illness in the community. It occurs when there is a break in the skin and subsequent bacterial infection—any number of reasons may account for the breakage—diabetes, cracks or peeling skin, peripheral vascular disease, or trauma. This includes the introduction of bacteria across the dermal barrier due to injection drug use. When individuals have a hard time bathing (for lack of private bathrooms, mobility issues, homelessness), face exposure from being outside, and lack adequate moisture replacement, cellulitis is frequent. For all of the reasons why someone in the inner city community might have cellulitis, nurses and physicians nevertheless associate it with drug use, when someone from Downtown Eastside Vancouver presents to a clinic or hospital with it. When a patient returns to the hospital because of another round of cellulitis, it is taken as an indicator that their drug use has increased or that they are destabilizing (e.g. they are newly homeless). These assumptions that have implications for the interactions that take place around requests for narcotics, as in the case of pain or withdrawal management. For interactions that are suffused with pejorative judgments about patients’ social identities, further difficulties in the health care system arise and self-discharge is not uncommon—the cellulitis is then untreated, the stereotypes of the drug user remain in place, and there is a notation in the chart indicating as much.

Missy was frequently in hospital for cellulitis throughout 2009. She described the way in which negative judgments based on figurations of drug addicts suffused her encounters within
the hospital setting, which on a number of occasions ultimately led to her decision to self-discharge from care. Below, she describes a typical encounter with an addictions consultant, who will be the one to sign off on whether she is prescribed methadone or not while she is in hospital:

> He [the addictions specialist] wants me to detox every time he comes to me. It’s, you know, ‘well, here you are again...’ it’s like, what the fuck? I’m not here for you. But I’m here and you’re here for me... ‘Oh, but when are you going to stop...’ shit like that. “The best thing...” and I don’t want to hear it. And then it’s, ‘well, we’ll start you again...’

> I’m sorry that I’m in and out of the hospital, you know? Fuck you too. I want to see you as much as you want to see me. He’s a real bummer. Then he gets into how much do you do, and how much heroin do you do, and how much up do you do. But then, ‘when are you going to change? When are you going to stop?’ And then the last time he saw me, he didn’t give me anything. Didn’t give me nothing. Well, fuck you! I would have stayed!

> Like, I do understand and realize that you know, yeah, I am an addict and I get carried away and everything, but I do know when I am sick. I do know when. But I can’t be [dope] sick and shit on, on top of that. It hurts. So the only choice I have is to either lay in that hospital bed and continue to feel sick and think about the long journey I have down here...am I going to go left or right off the bus, and where am I going to go after that, who’s going to help me out, you know? Or else, they’re going to help me and they’re going to fix me up, and then I’m going to be playing the game.

> I’m not saying I should say jump and they should say how high, it’s just that you’re addictions and you know, and I’m an addict and I’m sick, so fucking help me.

Given that illness within the context of HIV/AIDS and substance abuse often takes on the signification of personal failing, her description of the encounter between herself and the addictions specialist demonstrates how seemingly innocuous statements and encounters may not be experienced as such by patients. It might seem as though it is altogether appropriate for an addictions physician to initiate a conversation about detox and treatment; in certain instances, this may even be appreciated by patients. But as Missy describes the encounter, there are also negative judgments about drug use and drug users that underpin such statements.

> There is also a tendency to brush off patients such as Missy as being difficult or overly sensitive. Trivialization of personal experience is common for those who are understood to contravene the (masculine) norms of rational agency and we ought not brush off her discontent with the specialist so quickly. As Missy describes, she knows how she is feeling—that is, when
she needs methadone in order not to become dope sick, as well as when she’s ill enough that she ought to be in hospital. The physician’s attention is given, not to that, but to when she will start to fall in line with the expectations of appropriate behaviour. It seems plausible that her feeling that her own understanding of her body and her health needs are diminished because of her status as a drug addict. When she doesn’t go along with things (i.e. when she doesn’t “play the game”), she’s “shit on” and it becomes clear that, as the quote from the nurse in the previous section articulated, health professionals understand themselves to be the epitome of reason.

Freud speaks of the “typical symptoms” of an illness, admitting that these make people similar, which in turn makes the work of medical science possible, giving the diagnostician their bearings when approaching a patient (Freud 1957, 271; cited in Biehl 2005, 197). Packages of bodily markings and pathologies in HIV/AIDS care confer a category on those who present themselves to the clinical gaze, sometimes aptly (certain women did, in fact inject drugs), sometimes with less precision. In both instances, the relationship to an oppositional or stigmatized social identity generated conditions that made it more likely that individuals would withdraw from care, thereby furthering the association between the category and the typical pathologies. In contrast to Hacking’s reflexive view of looping effects, the social identity need only be ascribed, not necessarily internalized, in order to generate these dynamics. That ascription is strongly based on bodily features and markings (e.g. cellulitis), but it is also based on behaviours and interactions—women being “difficult” patients and their frequent appearances in the emergency department seen as evidence of their being chaotic—identities may even by ascribed simply based on one’s residence in the inner city.

Being ascribed drug-user status or membership by clinic staff is indicated by the type of questions that are asked at the outset of the clinical encounter, and how quickly one is asked (e.g. how early on in an initial clinical interview the question, “what drugs are you on right now” arises), staff reactions to reporting of pain and other supposed “drug seeking” behaviours,
inspections of the body for evidence of drug use (irrespective of one’s declaration that they don’t inject), and patients’ reports of a general lack of respect toward them. None of this is to say that questions related to drug use are inappropriate—they often need to be asked in order for an adequate intake assessment to occur. It is to say that the qualitative dynamics of the asking may implicate the substantive content of the tropes of addicts, junkies and the like as part of the encounter. These figurations are attached to one’s positioning within the medical field when one is identified as a representative member of this group, thereby altering possible courses of health-related action. Women who worked with me on the project would also read these messages off of the tacit meanings expressed in medical encounters—posture, sighs, pauses, eye rolls—as well as the direct statements made by health care providers.

Importantly, such readings were not only one-sided. As one of a pair of experienced home care nurses instructed me, using one particular patient as an exemplar, all it takes is “one wrong look”:

*She’s someone who watches every movement, every gesture. If you hand her the water too fast, if you don’t get her the water fast enough, if, the whole body language, she has it down to a ‘T,’ and if you make a wrong move, whew! She reacts very dramatically to that. She becomes snippy and rude, grabs the pills out of your hand, or ‘leave them there!’ She picks up on the slightest move, she’s very difficult that way.* (Nurse 1)

Although the nurse refers to this particular patient as being “difficult” to interact with, both she and her colleague went on to tell me that the woman’s reaction was not out of line, given what they themselves described to be the overall context of nursing care. In this context, the nurses include general presumptions of nurses as credible, rational agents, who rightfully define the scope of appropriate practices. The provision of health care services is taken by its representatives to be straightforward and rational, rather than the series of tactics, negotiations and jostled positions that women describe.

As I have discussed over a number of chapters, an experience of withdrawal or pain is taken to be less verifiable when the ascribed identity of the individual reporting such an
experience runs up against norms of credibility and competence; drug users are seen as being motivated to deceive providers regarding their pain and withdrawal, as such, staff are vigilant about signs and symptoms of illicit substance use in hospital as well as whether someone really ought to get more methadone or morphine. The ability to protest a judgment call of a health professional in the hospital setting is limited by presumptions of the authority of one party and the other’s lack thereof; this capacity is also structured by the particular setting, given that the degree to which pejorative group imagery has bearing on epistemic judgments varies across locations. Here is yet another way in which Hacking’s reflexive/cognitive view of looping effects falters—it is not simply determined by explicit policies related to particular identities (although this does have effects). The influence of social positioning based on identities makes it clear that action is often structured in ways that are neither explicit nor well articulated.

Lorraine Code describes this through a metaphor of rhetorical space—locations in which tacit norms structure and limit the kinds of assertions and utterances that are possible within the spaces, as well as the likelihood that particular utterances will be taken up and taken seriously (Code 1995, ix-x). Code writes that, “they are the sites where the very possibility of an utterance counting as ‘true-or-false’ or a discussion yielding insight is made manifest” (ibid). Her purpose in doing so is to move toward an understanding of knowledge claims as being made possible by the “textured locations where it matters who is speaking and where and why, and where such mattering bears directly on the possibility of knowledge claims, moral pronouncements, descriptions of ‘reality’ achieving acknowledgement, going through” (ibid).

Physically, medical settings are spaces that patients must present themselves at and subsequently be admitted to, on the authority of health care providers. This authority, to diagnose, admit, and treat, comes by way of medical education, licensing regulations, and social status (Ho 2009). In contrast, the drug user has only their subjective experience of pain or withdrawal to offer and is not often taken to be a particularly reliable informant at that. As
rhetorical spaces, presumed authority and rationality of health professionals confers suspicion upon those who would challenge the pronouncements and utterances of representatives of the medical institution. The medical chart, an inscription of rhetorical space, can serve to undermine women’s own accounting of their conditions when they are seen as failing to meet the norms of rational authority and agency.26

But relationships between ascribed social identities and the perpetuation of pathologies are not consistent across all clinical situations. Clinical spaces are variable in the strength of the associations between professional status and rational authority and in their reliance on type-casts for determining the working indicator-properties of informants’ credibility. Hospitals, staffed by those with specialist knowledge and designed for a relatively quick turnover of a large number of individuals, are less likely to operate as spaces that are responsive to drug users’ assertions. We can compare this to a community health clinic offering family practice services, where a longitudinal relationship is the goal, or to home care nursing services, in which nurses attend to patients in their own private spaces.27 It is not surprising that the view of drug users as attempting to hustle narcotics was apparent in the hospital addiction management workshop, whereas the defense of patients’ reports of pain and the troubles with accessing appropriate services in hospital came to me from community physicians and home care nurses.

Both Tina and Missy had experiences where they were not adequately treated for opiate dependency while in hospital. Tina was able to access methadone because her home care nurses had come to visit her in hospital—these were community nurses who understood and believed her assertion that she was dope sick and intervened on her behalf with other health care staff, who took seriously the assertions of a colleague. Missy was not so fortunate on one occasion.

Field notes, May 1, 2008

I go to see Missy in hospital; she’s upset about addictions services and wants to know whether I can do something to help her out. She says to me, “the methadone doctor didn’t wake me up, I need my meth upped, I’m jonesing with what I’ve got right now, still needing to use. Maybe you
could write a note in that book about it, can you do that? Or tell someone. Whenever you tell people things, it seems to get done a lot faster. I don’t know what kind of pull you’ve got, but…”

Of course I didn’t have any “special” pull, aside from the fact that it is harder for my assertions to be dismissed off hand, given my relatively privileged social position within the hospital setting, as a non-drug-using, Caucasian woman with medical and research training. The notation about the event in my field notebook also wouldn’t do much to help her, at least not then and there. What this example demonstrates though is how the content of tropes of drug use circumscribe the ways in which women from the community feel they are seen and treated within the medical system, which has implications for the acceptance or rejection of health care services, and the manner by which individuals feel as though they can best move through the health care system. Often, their movements in the health care system are understood in light of the negative aspects of their social identities, which further instantiates the notion that associations between drug use and negative health outcomes are natural, rather than constructed.

CONCLUDING REMARKS: DECENTERING THE SELF

This domain of the less than rational human bounds the figure of human reason, producing that “man” as one who is without a childhood; is not a primate and so is relieved of the necessity of eating, defecating, living and dying; one who is not a slave but always a property holder; one whose language remains originary and untranslatable…The figuration of masculine reason as disembodied body is one whose imaginary morphology is crafted through the exclusion of other possible bodies. This is a materialization of reason which operates through the dematerialization of other bodies… (Butler 1993, 48-49)

The traditional liberal vision of the self is premised by idealizations of rationality, detached judgment and the unity and clarity of categories. Appeals to the possibility of objectivity, unmediated access to pre-existing facts about the world, and a view of moral agents as a neutral, universal reasoner (Shildrick 1997, 2-3) are shared between the discourses of biomedical research, practice, policy and ethics, within which HIV/AIDS is but one field. In contrast to the conventional views, the “self” that is construed by way of interpreting and understanding lived experience is decidedly more fluid or fragmented than the conventional
philosophical accounts allow. We can now appreciate how these notions also structure women’s experiences within the clinical environment, shaping health-related behaviour and generating the material content (non-adherent bodies) of the associated categories (drug user).

Rather than seeing this as the debiologizing of pathology, I challenge the reader to consider my argument as a contestation of the nature|culture dichotomy, which far too often has an implicit role in the shaping of health policy. Knowledge and evidence generation very often does become suffused with unquestioned beliefs that are the foundation of stereotypes, such that bodies of knowledge can in fact perpetuate stigma and marginalization. My discussion of looping effects and the construction of social identity categories as well as the content of the categories and groupings, problematizes colloquial views that nature is separate from culture, and evidence is free from the bias of stereotypes. Each instance of a woman withdrawing from health care services in which the milieu of the clinic includes negative images attributed to her social identity increases the likelihood of untreated opportunistic infections, advancing organ dysfunction and diminished overall health. In that way, we might think of the materialization of HIV-positive women’s bodies as pathological as an upshot of their being held in opposition to the idealized views of rational agency. In various ways, we see the pathologizing of those uncritically taken up as Other.
Populist figurations of drug users and individuals living in urban poverty—as mentally ill, irrational, and irresponsible—lend credence to suppositions that non-adherence to therapy is predictable for such individuals, and can be explained in light of a failure to attain standards set by ideals of the self-as-rational-agent. Ideas about personhood and agency are intimately entwined (Kratz 2000, 137). Unsurprisingly, then, failings with respect to following medical advice are widely understood as failings of rational agency. In Chapter Five, though, I also suggested that ascriptions of particular identities have a way of generating the conditions and environments in clinical settings that lead to non-adherent actions, particularly when the figurious content of ascribed social identities justifies treatment that is felt by patients to be discriminatory, disrespectful, or to diminish their sense of control and authority over their experiences in the medical system. Drawing on my own empirical work in clinical environments, I leveled a series of criticism against conventional models of adherence on the grounds that the philosophical underpinnings of these models contribute to a milieu in which the HIV-related pathologies statistically associated with the identity categories employed in research and clinical practice are perpetuated.¹

To this, I aim now to add another layer of analysis, honing in on issues of agency within the domain of HIV/AIDS care. Much of what has been said thus far has been in the spirit of critique—an attempt to bring to light the sometimes hidden and often under-examined aspects of the socio-historical reality within which adherence exists. It seems timely then to begin to offer an alternate explanation of non-adherence to ART, one that has its grips on an enriched, more nuanced account of agency and the self than the rationalist views that have been at the heart of my analysis.
I begin this chapter by examining challenges that a number of study participants faced in their efforts to obtain or maintain their use of HIV-related medical services. Specifically, looking at field data that focuses on acts of non-adherence will clarify how it is that HIV-positive women in Vancouver’s inner city setting attempt to negotiate health care services in light of the dominant social imaginaries associated with rational agency, along with the oppositional imagery ascribed to those women who are non-adherent to ART. By speaking of “negotiation,” I do not mean to invoke a liberal notion of contracting. Rather, I aim to refocus attention away from the issue of “access” to care and toward the qualitative, interpersonal dynamics of care. Access is something of a misnomer when it is applied to a substantial proportion of the inner city community: as I described in Chapter One, health care utilization statistics indicate that women utilize high rates of primary, emergency, and nursing care, well as various harm reduction services (Shannon et al. 2005, Kerr et al., 2004, Solomon et al., 1998). As the subsequent chapters have detailed, continuity and longitudinal aspects of care are complex and challenging issues that need to be contended with.

Making the terminological shift to “negotiation” is meant to acknowledge that health care providers and their patients have different perspectives and often different interests; that elements of persuasion are at play in encounters on the part of the parties involved; that actions and their effects not only take place through those performing the action, but are shaped by wider fields of signification. It is important to note that meanings attached to actions are not always mutually recognized amongst different actors. If agency is about action, and actions within the medical system are taking place under contested or disagreed upon descriptions, then what may appear from one perspective to be a failure of rational agency might be instead conceived of an alternative mode of agency altogether, one that a patient understands to be oriented to maintaining well-being as they judge it.
Some of what I have called “fields of signification” include ways in which HIV-related illnesses are construed and understood as forms of personal failure, the interlocking forms of authority that limit control over oneself depending on one’s social and economic positioning, and figurations and imagery that posit drug-using women to be non-integrated, irresponsible, or irrational. These are exemplars of how emotional and moral configurations of interpersonal and institutional relationships function as “structure” (Ortner 1989, cited in Wardlow 2004, 5), powerfully shaping different possibilities for women’s health-related actions. I argue that in many instances there is no straightforward “path” to implementing health care decisions for these women; they must navigate a tortuous route through clinical and personal spaces that are often experienced as (artificially) incommensurable social worlds. When those circuitous paths are closed off, and women are unable to influence the health field through negotiation of what constitutes, for them, appropriate care, their recourse is either to acquiesce to or resist the medical system.

The challenges of acquiescing to the demands of a medical system (for instance, having one’s sense of illness as failure and transgression reinforced) make resistance to care a more acceptable option. Ultimately, this may culminate in a refusal to participate in the field of health care at all, enacting what Corrine Kratz terms negative agency (see Kratz 2000; Wardlow 2006). As a mode of agency, I argue that negative agency is deeply connected to the ways in which women in the inner city community are ascribed aspects of personal identity that oppose normative views of the rational self. This chapter explores the concept of negative agency, considering whether non-adherence might be better understood in these terms, as opposed to its present interpretation from a biomedical perspective as amounting to a failure of rational agency.

There is, embedded in this discussion of non-adherence and negative agency, a continued appraisal of the limits of liberal philosophical accounts of rational agency. I intend to carefully engage with what I take to be a serious and sophisticated contender in this line of philosophical
thought, but will ultimately argue that such an account cannot suffice to explain all it hopes to explain and may, rather surreptitiously, reinforce positions of privilege and marginality—the very injustices and inequalities that liberals are concerned to avoid or provide redress for.

**NON-ADHERENCE AND NEGATIVE AGENCY**

As I have described, familiar narratives concerning liberal views of agency within the field of health go something like this: being in control of one’s health and maintaining health is reflectively endorsed and internalized by individuals, such that they take actions toward health and act responsibly with respect to that end (Lock 1998, 50). Similarly, awareness of one’s personal risks with respect to disease states can be widely expected to motivate changes in behaviours, such that the individual is an agent of prevention, responsible in certain ways for her health (Lippman 1998, 66). Those who do not act responsibly toward their health in a variety of capacities—failing to manage risk, not complying or following through with treatment or interventions—demonstrate failures of rational autonomous agency. Moral psychology literature envisions those who fail to carry out intended actions (e.g. failing to ingest medications or show up for an appointment) as non-agents when their non-actions are reflective of a kind of passivity; similarly for those who are “driven” to act by external desires such as addiction (Arpaly 2003, 5). Hence the need for health care providers to provide adequate information, engage in motivational interviewing techniques, offer incentives to ingest medication each day, and failing that, use more paternalistic measures to ensure that those who continually fail to function according to ideals of rational agency remain adherent. Such individuals may or may not be able to regain full agentic status upon a return to “health.”

The account of agency I intend to give, by way of an interpretation of women’s acts of non-adherence, is meant to disengage from a traditional liberal understanding that agency is about processes of deliberating, choosing, integrating, and then acting. Instead of imagining that non-adherent behaviour is some species of agentic failure, I am re-interpreting the contours of
agency by re-interpreting their (non)actions as a particular mode of agency. The alternative I am suggesting envisions non-adherence as a refusal to partake in actions within the health care field: a mode of agency that resists actions that are reflective of normative standards and expectations, carried out so as to protest some aspect of the normative.

Holly Wardlow, following Corrine Kratz, uses the term *negative agency* to depict agentic events that mark a refusal to cooperate with others’ plans and endeavors, whereby the agent withdraws their energies from a particular social field. As I employ it, the term denotes a characteristic mode of producing actions and effects within the health care system—a withdrawal of energies and activity from this social space in spite of a continued desire to receive the benefits of engaging in health care services. With respect to antiretroviral therapy and adherence to other forms of medical advice, we can think of the concept put forward by Wardlow and Kratz in the following way: the women I followed, when they were non-adherent in various ways, would move themselves outside of the health care structure (to greater and lesser degrees) or attempt to negate their positioning within the structures that are put in place for their medical care but which offer very narrow pathways for treatment and problematically define their identities.³ This form of agency enables those who enact it to exert influence and produce effects where they might otherwise be unable to, or to manage situations where following the expectations set by the normative ideals is problematic for the agent, psychologically or logistically.

The account of action and of agency I am offering lines up, moreover, with feminist critiques of conventional conceptualizations of agency and the rational, autonomous subject of traditional liberal philosophy. Writes Letitia Meynell:

Against the traditional view of the radically autonomous subject, feminists argued that the self is not radically autonomous, but is importantly relational. While some theorists have understood the self as emerging solely through the interactions of close interpersonal relationships, others have understood relationships to include “the full range of influential human relations, personal and public…” (Sherwin 1998, 19). These thinkers have argued that the agent cannot escape her
political context; the agent’s positions in social hierarchies influences what she can know, what she wants, and what moral rights and obligations she might have.

(Meynell 2009, 7)

It will become apparent that the events I will describe as “paradigmatic” of negative agency are actions that culminate in non-adherence. Actions leading to non-adherence result from relational elements of the self—namely, the influence of ascribed social identity on one’s positioning within the medical system and in wider society, which shapes the possibilities and conditions for agency. Somewhat akin to sabotage, my suggestion will be that as a mode of agency, negative agency is predominantly enacted by individuals whose ascribed identities are normatively oppositional; in the case of non-adherence to ART, selves who are seen within the social imagination as opposing norms of rationality.

Field notes, May 1, 2008

Carly and I go into the office, she’s there to talk to her doctor about when she might re-start her HIV medications. She has previously been to see the infectious disease specialist at the clinic and has discussed getting back onto therapy. Her CD4 count is 260 – she could go on therapy if she feels she’s ready, but her primary care physician is worried that she won’t be adherent. It’s a relatively simple NNRTI regimen she’s been prescribed, but he is concerned that she’ll “blow the whole class” if she’s not 100% adherent, which could lead to drug resistance. He says she might be better off waiting until she’s more stable, at which point Carly gets upset, prompting him to ask her, “are you stable, really?”

She starts crying, saying to him, “The last time I used was two days ago, it was just one paper, it didn’t even do anything. I’m not using every time I get my cheque, I’ve got food in the fridge, I’ve got money, I’m dressed warmly enough, I go to bed at 8 p.m., I’m trying to do everything right to be healthy.” He sits quietly, letting her finish. There’s no resolution about the start date for her ARVs by the time the appointment is concluded.

Afterward, we’re standing outside the clinic when she says to me, “I couldn’t believe it when he said that. I just feel totally worthless, like I’m trying here to get things in order, and nobody is willing to see that I’m doing my best. Look, I’m hardly using, I don’t work the street anymore, what else do they want? It just makes me want to say ‘fuck you’ and go out and use.” Then she says, “I’ve got to get out of this neighbourhood, it’s killing me. Seriously.”

Looking back on my field notes after so many months in the community, a number of features made this occurrence seem to me to be paradigmatic of a challenging attempt to negotiate care. In this instance, Carly was attempting to re-engage in antiretroviral therapy. She
had been non-adherent to her regimen six months prior and had eventually stopped the medications altogether. What was compelling about this interaction were the ways that Carly had been attempting to demonstrate to her physician that the previous “chaotic” aspects of her life were now in many ways under control—she was using less and doing the things that she had thought they would want to see her do (get enough sleep, adequate nutrition), but this did not change the assessment of her lack of stability. She was also in the midst of carrying out other actions that the clinic staff had indicated would be indicative of her “really” being motivated and ready to adhere—following through on appointments made for her with the infectious disease specialist, for instance. On various levels, she was demonstrating her concordance with widely accepted models of rational health behaviour.

The frustration she felt when her efforts went unrecognized led to a response that seemed to confirm for her physician that she was not in fact stable, as the rhetorical tone of his question indicates. What is particularly noteworthy about this dynamic is highlighted by Carly’s remarks after we left the clinic: that she felt “totally worthless” when it was the case that nobody would acknowledge her efforts and that “it just makes me want to say ‘fuck you’ and go out and use.”

Here is a situation in which the dynamics of the encounter are able to generate the conditions that the physician assumes are already in place—Carly begins crying, is seen as being unstable, and the interpersonal interaction that follows generates a situation in which her response is to want to pull away from care and engage in further drug use. This was not a one-off encounter between Carly and her physician. Other women would become upset when they felt they were being inappropriately accused of thwarting their health through actions such as on-going drug use, saying to me, “I’ll show them a binge…”

Akin to being questioned about “stability,” which Carly felt was insulting given her various health-related efforts, Missy interpreted the times that she did not receive adequate methadone for withdrawal while in hospital as a test of her motivation to engage in treatment.
Her view was shared by others on the ward. Her remarks at the end of the previous chapter indicated as much: swearing as she described how she wasn’t prescribed methadone but was put through a gauntlet of questions concerning when she was going to stop using, she said that she would have remained in hospital, had the encounter gone differently. “I can’t be [dope] sick, and shit on, on top of that.” The sense that she was being tested would often generate feelings of contempt and indignation at the very prospect of continuing to engage in the health care system.

Field notes, March 31, 2008

Missy asks me why the addictions specialist would have come to do her methadone consult just as she was coming out of a general anesthetic and subsequently declare her too “sleepy” for methadone. “Is it some kind of thing, they’re testing me, to see if I really want to go through with all of it?” she asked. Her friend, John, is sitting on the balcony with us and adds, “like to see if you’re committed, that you’re going to stay?” John goes on: “She’s dope sick man. It’s bullshit. They expect you stay and they don’t give you nothing for pain.” Missy says that she’s been in for two days and hasn’t had anything. “It’s no wonder people take off.”

Women would also explain to me dynamics between other individuals and health care providers in clinics and on the hospital ward in similar terms, interpreting the actions of other patients, which were taken by staff to be problematic or irrational behaviours, as perfectly legitimate responses to intolerable situations. Telling me about Justin, a man on the ward who had taken off to buy alcohol and had came back to the hospital intoxicated, Missy stated:

[the staff person] triggered him, with all the control stuff…his cigarettes, controlling his money. He wakes up in the hospital, with all of these restrictions. He just ripped off the ankle bracelet the one day and took off, got drunk.

Taking Missy’s account of the events seriously means that we cannot presume that this was simply a case of Justin being childish or irresponsible. It is my contention that a standard interpretation of the events from the medical perspective—that Justin’s taking off to get intoxicated demonstrates his inability to rationally control his behaviour and engage in health care—is based on a set of often unarticulated normative standards that are employed within clinical domains. But are these standards truly universal, and why ought we presume that the interpretation of Justin’s actions against this standard is the legitimate one? Although Missy uses
the psychological construct ‘triggering,’ indicative of a reactive or emotive response, the wider context of our discussion was that Justin’s actions were nevertheless a justifiable response to a situation that was untenable.

Attempting to contend with the demands of HIV/AIDS care in a wider milieu of serious social and economic disadvantage can result in situations where the straightforward path, from intention to action, is exceedingly difficult, or in some instances, impossible. As each of the examples I have discussed thus far suggest, this is often for reasons beyond simple logistics. Acts of non-adherence have a particular quality to them when they are carried out by those who lack certain forms of privilege—people whose lives are shaped by institutional, emotional, moral, and imagistic structures that are often oppressive. In that respect, it is significant that Carly herself identified a relationship between the clinical encounter, her response to it being a withdrawal from the domain of healthy behaviours, and her position as a drug user living within the inner city community. The demands of the medical system may mean, for example, endorsing one’s relatively disadvantaged position within a given social field (including health) by submitting oneself to further authority and loss of control as well as by having one’s pain left untreated, or it can mean that one’s other ends (outside of the health domain) are not going to be met.

When a patient is faced with a clinical situation they find intolerable, they have one of a few options: (1) they might acquiesce to the demands of others (or an institution), carrying out what is expected of them, while incurring the personal (emotional, moral) burdens and costs of the interaction; (2) they might attempt to find an alternate route to achieve what it is that they are after, inciting pejorative descriptions of their behaviour as manipulative or underhanded; or (3) they can refuse to cooperate altogether and withdraw from health care services. It is the latter case that I am referring to as negative agency—the disconcerting feature of this mode of agency is the continued association between non-adherence and the social identity of the agent (e.g. as a
drug user), along with the continuation or worsening of HIV-related pathology. These possible modes of action within the health care system are interconnected: as the burdens of acquiescing to care build, the desirability and required effort of alternate but circuitous routes can make the negotiation of care more problematic; as the circuitous paths lengthen and the incommensurability of health-related ends with other needs and ends intensify, challenges within the health care system have a way of boiling over into negative agency.

**ACQUIESCING TO CARE: TROUBLES WITH THE “RATIONAL” OPTION**

When patients find themselves attempting to negotiate care in a clinical situation that is being informed by issues of categorization, ascription of transgressive social identities, invasive and external controls, etc., there are a number of potential courses of action that they may subsequently undertake. It is certainly the case that the women I had followed would, at times, go along with what was required of them in order to continue to participate in the health care system and receive its various benefits; they often did this volitionally—wanting to diminish the challenges of illness and take steps toward improving their health, as they understood it. But there were often costs associated with their engagement in the health care field. I have already suggested that some of these costs are physiological—not being treated for withdrawal, for example, or having to go through painful procedures, while also having testimony of pain met with suspicion. As the latter situation indicates, costs can be psychological or emotional as well—not being seen as reliable or credible regarding assertions of pain, or having to put up with being “shit on,” while simultaneously understanding the overall context of your condition to be a result of personal failings. The particularities of health care encounters can exacerbate one or both of these sorts of challenges, as the examples below indicate. These articulate what it is like for some women to try and go along with their health care plan, “play the game” as Missy would sometimes say.
Angel

In Chapter Four I quoted Angel, a woman on salvage therapy and receiving daily medications through a home care program, as describing the trouble with being adherent to HIV care as being a problem of wanting *just one* day away from it all, but knowing that day after day after day, her nurses would be coming back, and that this had to happen in order for her medication to continue to work. With one pair of the nurses who might visit her, she has what she describes as a very good relationship—their presence in her SRO room every morning is not usually intrusive, particularly as compared to some of other of the nurses who might bring her the daily medications. Angel receives one medication through intramuscular injection, which is a painful and unwelcome start to the day; the difficulty of the regimen is often made better by the couple of nurses who try to give her some control over the encounter, not rushing her, having her place the intramuscular syringe pump where she feels it will hurt the least. But it’s a challenging thing to have done each and every morning. Of the two nurses Angel described as the ones who “have been there for me through a lot,” one nurse described what it was like to try and work with her when the daily injections were problematic:

One day...there was no way, she would just lay there and lay there and lay there and I was “Angel, Angel...” (whispering) and, no, no, no...and eventually she, ugh...and the second shot killed her, totally killed her. And that was totally nerve wracking for me. Not only have I woken her up, and she’s pissed off about that, but now I’ve also hurt her. So I felt very upset by the time I left there [that day]. (nurse 1)

For Angel, the difficulties of partaking in the daily care are lessened to some degree by her relationship with the two nurses who try to ensure as best they can that she is in control of the encounter—talking quietly, not shaking her awake or rushing her, having her place the injector. In contrast, the difficulties are intensified by other members of the nursing team who were described to me as saying, “*come on girlfriend, we ain’t got all day,*” when she’s slow to rouse or turn over.
Pearl

Pearl, an Aboriginal woman in her late forties, also receives her HIV medications each day from the home care nursing team. Two of the nurses on the team in particular have seen her through a number of attempts with detox and recovery, and she has described their tenacity in following her health as a positive aspect of their relationship. Their continued engagement with her is unique in some respects—Pearl is a woman whom the two nurses described as someone who has been “written off” by many people in her life—other health care workers, family members, foster parents. Their on-going relationship with her is tenuous. When she does start using drugs and alcohol more frequently, she feels terrible about herself and her substance use and is embarrassed to see them. Her sense of shame is heightened by other health care providers who, when frustrated with Pearl’s drug use, have lectured her, saying that if she’s going to keep using they won’t keep coming back each week.

Telling me about what it is like to receive daily nursing visits with medications, Pearl had said that she usually loves seeing the nurses. She noted though that there were instances when a different nurse would be the one to deliver her medications and she had felt that she was being ignored or rushed when trying to raise a health-related concern in such instances:

That other [nurse] …she just drops the meds off, ‘here, take this,’ and leaves! I’m standing there talking [to her] and she just leaves! Or if she’s with [my usual nurse] and she and I are talking, then she’s standing there with her [arms crossed, tapping her foot, waiting] …

The signification of the clinical encounter is altered by the interpersonal dynamics. One of Pearl’s regular nurses explained to me the interpersonal difficulty that Pearl describes above, saying:

A lot of the other nurses [who] see our patients, deep down, [they] feel that they should not be seeing them. So [the nurses] start off with an attitude that deep down, they’re not happy about having to go [to see the patient] every day, and that colours how you react to people. (nurse 2)
For both Pearl and Angel, and I submit for many other patients, the qualitative aspects of the encounters contribute to their meaning and interpretation. Along with their assessment that judgments concerning whether a patient is deserving of care influences the qualitative aspects of health care interactions, Pearl’s regular nurses also described to me how a patient’s lack of credibility impacts relationships in the health care field. Individuals in the community are all too often assumed to be lying or pill-seeking. In such cases, epistemic authority is withheld on the basis of perceived membership in a socially constructed group, excluding presumed group members on the basis of a lack of credibility (Daukas 2006, 109-110). These qualitative features—desert of care and presumed lack of credibility—are two elements (among many) of the conditions under which interpersonal relationships develop, between health care providers and patients who are perceived to be members of the group “drug users.”

The conditions under which relationships develop and health decisions occur animate the ways in which care is negotiated. The interpersonal elements can, for example, shape what it means to take part in health care services—carrying out a health care plan can have the quality of “acquiescence,” rather than “engagement” or “participation.” Over time, these qualities also inform what it means to acquiesce to the demands of the health care system, particularly when the qualities of the interactions are layered with systematic and regular challenges in care, such as lacking control over the events that take place, being treated rudely on a regular basis, perceiving disrespect, or contending with the impatience of a health care worker. Ultimately, these features alter the meaning that the home care patients would attribute to their visit. What would in some instances be described to me to be one of the best parts of their day could become a reiteration of illness and failure. The ability to contend with daily HIV care depends on a great extent to experiences within the health care system and interactions with its representatives. The encounters that the women articulated as problematic are the same sorts of encounters that generate the conditions under which negative agency becomes a mode of agency in health.
At various times, some of the home care nurses I had observed over the course of the project would identify how they felt they could fulfill their role maintaining adherence in a way that was non-invasive, even when it was a daily part of someone’s care. By providing a means of access to physicians that bypassed the drop-in schedules at the community clinics, by doing regular health assessments, by offering rides to appointments or arranging various forms of additional support, they were not just showing up and dropping off pills, making a tick on the medication administration record (MAR) and then getting to the next patient.

"Being there to help someone navigate through the health care system because we are professionals is huge, because it’s not just [meds] ... there’s are all sorts of other stuff that comes up and they have no hope of [getting] themselves to get to A, B and C. (Nurse 2)"

My experience with women in the community leads me to concur with the nurse’s statement, that having a trusted individual who has access to the necessary avenues and goods of the health care system to serve as advocate and help negotiate what can feel like a complex and hostile bureaucracy does help to minimize the challenges that the demands of HIV care can bring. For those women that described their relationship with their home care nurses as close, personal relationships, the nurses’ efforts also helped to diminish the sense that every aspect of their life is medicalized.⁵

While the above discussion points out a number of ways that HIV/AIDS care might be improved upon in the community, I want to use the nurses’ roles as advocates and collaborators to highlight how their patients’ overall ends of “health” may not always be straightforward to carry out. Having difficulty navigating the bureaucratic regulations of Health Authority clinic in order to carry out health-related intentions should not be taken as being merely the result of incompetence or irrationality. Naomi Scheman argues that when individuals who are faced with serious and systemic forms of disadvantage lack the ability to take a straightforward action, unable to smoothly carry out their intentions, they are often faced with the prospect of employing
circuitous routes to achieve their ends. In such instances they are subsequently remembered as having transgressed normative expectations (Scheman 1997, 125). The modes of agency set as ideal by traditional liberal philosophy—unified, rational autonomous agency—require what Scheman calls an “elaborate collaboration” on the part of a compliant social structure, which is provided primarily to those with privileged identities (ibid). The liberal precepts of the unity of agency and an integrated, rational self presume that such a compliant social structure is universally available.6

Living in opposition to the normative standards of reference forces disruptions of unity (Scheman 1997, 130-132). Using the metaphorical language of roadways, Scheman writes:

…the necessary survival strategies of the oppressed make these marks of full, moral humanity unattainable: Manipulation, deviousness, fickleness, and other stigmata of less than fully straightforward, solidly transparent subjectivity can be the signs not of defects of character but of the only available ways of getting by in a hostile world. If the straight roads are ones that require tolls one cannot afford to pay, and if they are laid out not to go where one needs to, then one has no choice but to find alternative routes. (Scheman 1997, 125)

Scheman makes clear that for individuals facing systemic forms of disadvantage on the basis of group membership, the you that chooses often cannot do so in a straightforward fashion—their various ends are fractured and incompatible with one another. If “choosing” to stay in the hospital to complete a course of antibiotics means having one’s credibility or moral worth regularly called into question, or having one’s means of survival undermined because of standard procedures (e.g. having to report in to the nursing station every six hours), adhering to the requirements of one means negating the importance or value of the other. Both ends—carrying out actions toward health-related desires and maintaining a sense of dignity—cannot be satisfied. Neither of these are ends that are easily given up, and neither are irrational to hold.

At times, women would attempt to carry out both, as best they could. They might remain in hospital but refuse to carry through with certain procedures or consume particular medications; trips off the ward might be more frequent. In such instances, traits such as
deviousness and fickleness become character traits that are attributed by staff in light of such actions. Traits such as these are reinforced by the populist images of drug using women as chaotic, hustling, and manipulative. As a number of feminists argue, the images and schemas used to interpret the actions of non-ideal Others are formed in response to the simultaneous necessity and impossibility of the demands of the unitary self. Misogyny and bigotry, for example, can be understood as the result of the despised attributes being projected onto marginal and excluded social groups (Meyers 2004; Scheman 1997; Kristeva 1991). “Choices” are frequently forced alternatives that (purposefully or not) safeguard structures of privilege and maintain the boundaries of marginalized and stigmatized identities (Scheman 1997, 149; Lugones 1990, 503). Even the alternative routes that are open to those who lack privilege are problematic—there is a propensity for such routes to seem irrational or indirect, and taking such courses of action is seen as an indicator of a manipulative and underhanded character. This maintains prejudicial stereotypes along with the fiction that the ideal self is possible (for some) to achieve.

The interlocking assumptions that “normal” people collaborate with their health care providers to come up with an acceptable and straightforward health plan and that substance using women are a hard-to-reach group who don’t appropriately access care can be problematized on the grounds described above. The “access” literature orients the problems of health care services to one of getting a difficult group of patients in the door. At the same time, there is limited justification for altering the delivery of health care services, if it’s the case that those who do not collaborate fail to do so because of individual pathologies of rationality. The system remains untouched by the criticism that certain groups of people can’t seem to get with the program because the image of an ideal populace that does not unnecessarily consume health care resources remains in place. As projects of knowledge and expertise, the access/adherence
literature and the practices of HIV/AIDS care may thereby contribute to the ways in which social positions of superiority and inferiority are carved out.\(^8\)

The previous chapter’s discussion of looping effects and the continuation of HIV-related pathology makes it clear that circuitous routes are constructed in relation to particular social identities and are not simply the consequences of bad behaviour. For women in the inner city community, “health” is not a matter of going easily from intention to action. The populist view (often shared by health care providers), that women living with HIV ought to be trying harder to follow through with medical care, ignores how the temporally extended nature of the goal of “health” is often impossible to reach; it ignores women’s previous experiences in the health care system, as well as the struggles of daily survival for women who are impoverished and facing serious illness. Presuming that following through with medical care just is rational action may have the inadvertent consequences of perpetuating pathology and marginal identities, insofar as the demands made upon women by the system can be impossible to achieve.

Within the medical system, the metaphorical roadblocks that Scheman gestures toward are the psychological and logistical barriers to navigating large institutions and bureaucracies whose policies and procedures have been designed by those at a distance from the lives of the individuals affected by them, and for different purposes. Missy would often only go into hospital after she’d been up for a number of days at a time, working and using crack to stay awake. Being in hospital was stressful for her, so she felt that she would be better off to go there when she knew she could sleep through the worst of it—the admissions procedures, initial blood work and diagnostics. Of course, this meant that she was “drowsy,” not having slept in three days and also being sick enough to be admitted, and as a result she would often not get methadone for some time. In such cases, she would still start to become dope sick (experiencing withdrawal) and if a friend couldn’t come up to the hospital with opiates or she couldn’t acquire any from another patient on credit, she would be gone again—another AMA noted in her chart.
Additionally, her strategy of dealing with admissions would, at times, complicate the ability of
the admitting staff to get her medical history. Showing up at the tail end of a long period of
heavy crack use also fuels speculation that patients are coming to hospital to try to acquire free
narcotics, rather than seeing that they have tried to make the hospital visit fit with the other tasks
they need to perform on a day-to-day basis. With “evidence” of her lack of credibility in place, a
whole other series of actions and encounters might then occur.

From the perspective of the institution, it is reasonable to require that patients seeking
hospital care not be intoxicated. But for patients who have been through the admissions
procedure time and again, who are dependent on opiates and know that they are often unable to
receive methadone for some time after they arrive at hospital, going through the emergency room
doors without having used heroin is problematic. When procedures become more stressful and
their anxieties around withdrawal intensify, they are more likely to lash out—but then they are
labeled as difficult or as being intoxicated and reprimanded for their behaviour.

ROADBLOCKS TO CARE OR LEGITIMATE DISINCENTIVES?

Field notes, January 24, 2008

I come down to the fast track area of the ER and tell the nurse that I’m looking for Carly. He
looks at my hospital ID badge and I tell him I’m a friend of hers, and he shows me to where she
is. She’s sobbing quietly in the corner of fast track. She’s mad about how she’s been treated by
the IV nurse, saying that she was mean to her. She tells me that when she complained about the
discomfort from the IV line, she was told by the nurse, “I’ve been putting IV’s in junkies for 20
years.” Carly says that they have no idea what it’s like, no idea. She hasn’t had methadone in
nearly 36 hours. She didn’t get her morning dose because she came up to the hospital at 7 this
morning and she usually gets her methadone at a neighbourhood pharmacy at 6:30 am.
“Them’re punishing me,” she says. “They say I’ll get it when I go up to the ward, but it’s 3:30
[pm] now, I’ll get up there they’ll have to do their thing up there, then it’s going to be like 7
[pm] before I get anything.” She tells me that her normal thing is just to say fuck it and take off.
She says she isn’t going to this time, but she can’t stand this shit.

Carly’s experience demonstrates how the logistical roadblocks (needing opiates, having
limited access to methadone, being well aware of the usual complications with addictions
services) can intersect with psychological roadblocks (the feeling of being punished, being called
a derogatory name), all of which make it difficult to carry out health-related intentions. In this case one of the biggest issues was a derogatory statement made by a health care professional, but interactions need not be so explicit to convey the same meaning. Carly did “stick it out” and was subsequently admitted to one of the wards. But at other times when I had been with her in the community, she would simply “forget” or dodge a particular appointment, or would see a physician other than her usual one, because she knew that she would be expected to take herself to the hospital, or go through with additional tests that she was uncomfortable doing. And while she needed some form of healthcare and wanted to be able to have her problems documented, the hospital might be out of the question at that particular point in time. She was subsequently “known” to be someone who would poly-doctor and who could not be relied upon to follow through with health care—negative images that reinforce the marginal identity associated with drug use.

Aside from simply examining what roadblocks exist for those who are using drugs and trying to navigate the medical system, we need also to ask why it is that the roadblocks are thrown up. There is a tendency, I think, to presume that illicit activities just shouldn’t occur, and that any consequence of them is a legitimate one for the actor in question to bear. Thus they are not “roadblocks” so much as they are justifiable disincentives to problematic courses of action. There are some obvious ways in which this interpretation of the challenges of negotiation or navigating through the health care system is unfair. Clearly, the derogatory comments and pejorative images of drug users and the stigma attached to populist figurations and tropes are problematic and ought not to be thought of as justifiable disincentives. But in order to problematize what might be understood more commonly as a legitimate disincentive, we ought also to examine exactly how the barriers to negotiating health care service use are constructed. I do so now, by examining one section of an interview with Dee, an Aboriginal woman originally from Manitoba and Ontario. Over the years, Dee has had numerous struggles with adherence to
ART, although her personal assessment, like that of her health care providers, is that she is able to do well with adequate (daily) nursing support.

Dee and I got to talking about what it was like to try and negotiate the use of health care services in light of being part of a drug using scene. She described her current challenges with her health care as relating (in part) to her living in the inner city community, where she gets caught up in trying to make money or provide favours (such as subletting her room to other women to use for tricks) in order to keep an “in” on the scene:

[I can’t] have time for both, or something. One doesn’t [allow] the other. Yeah. So it’s like you have to choose one or the other, one will require you, so you can’t be there for the other.

Right now you’ve got one foot in the fire and one foot where you want to be. And that’s how [the other users] look at it, like, ‘choose a side.’ Like, ‘you’re taking part or you’re not.’ Like you can’t be on both sides, cause then you’re yanking their chains almost, like, ‘you think you’re somebody?’

...They get rotten on you because they want to know which side you’re choosing. Sometimes it’s overwhelming, but, it’s about my own decisions anyway. Not about what people think about me. Like about choosing between the sides I want to go on... or, you have to choose one way or another.

On the face of it, Dee’s description gestures to the need to make a choice about which side (health or drugs) she’ll be on and the impossibility of following through with her health needs when she’s involved in the drug scene in the neighbourhood. This could very easily be taken to echo the conventional view that drug users’ difficulties with adherence and with the health care system are simply of their own making, and that a different “choice” would remove the kinds of obstacles that I have been describing. However, this conventional response, that “health” and the drug scene are mutually incompatible and that prioritizing health is the rational thing to do, presumes that the unified rational self is a generic normative ideal that is universally available to those who would just make the “right” choices, and that a fragmented sense of self is one’s own doing. The “common sense” response fails to see the role that the normative ideal plays in
generating conditions of fragmentation. For those whose daily lives do not match this description of the self, experiencing an incompatibility between different ways of being in the world is commonplace, perhaps even unremarkable, and rarely a matter of “choice.”

Maria Lugones makes this point in her discussion of what it is like to live as a bicultural person in an ethnoracist society, arguing that the desires, beliefs, intentions—the things that are the supposed foundation of agency—are not possible in one reality, even for as much as they might be required in another (Lugones 1990, 503-504). Bicultural experience, in social worlds where difference is exclusionary, generates competing and incompatible ways of being in the world(s). The experience of such individuals is that of moving across realities, of being different and non-unified in each (506). Thinking about personal identity and the categorization of individuals as drug users, it’s clear that not all of the identity-related constructions I’ve been concerned with pertain to ethnicity, or what might generally be thought of as “cultural” identity. Of course it does seem to be the case that for Aboriginal women who are using drugs, the navigational troubles mount, given the ways in which their social positioning along a variety of axes contravenes the generic universal. That said, I think that Lugones’ point can be made with respect to the aspects of personal identity that fragment or exclude one from achieving the norms of rational autonomous agency, and can be used to explain some of the ways in which oppositional identities generate the navigational troubles that the women in the project describe. What matters is that an action is understood on very different terms in one space as compared to another, and the different understandings are connected to the social identity of the agent in each of the spaces.  

We saw this with the alternate meanings attached to the notion of “hustling.” It could likewise be said of ways in which women experience a level of control over themselves in their daily street life but have that control abruptly shorn from them in the clinical world of HIV care. In these instances, the alterations in the meaning of hustling and in experiences of control relate
to the role that pejorative figurations and tropes of drug users play in clinical settings, where women are faced with diminished credibility and views of deviance ascribed to their presumed social group. These figurations still exist in the inner city community. However, the significance of them, in determining how actions, demands, testimony, or other forms of interaction are carried out, will be different from clinical spaces. In clinical spaces (both physical and rhetorical) the explicit rules and tacit policies of institutions and organizations presume the normative ideal to be an appropriate reference standard and the “drug user” oppositional to that.

Dee’s experience of inhabiting incommensurable social spaces was not unique amongst the women I followed throughout the project. Missy faced numerous challenges carrying out health-related actions such as staying in hospital, or showing up to a pharmacy or her housing unit each morning to take her ARVs or methadone, given that her primary capacity to make her financial ends meet was through the informal networks that enabled her to deal, or to acquire favours that would mean the ability to access rock (crack cocaine) and heroin when she didn’t have any money. As an example, one of Missy’s main troubles with following through with HIV medications and methadone was the requirement that she show up at her housing unit or at a particular pharmacy at the same time each morning. Her housing unit was unable to do outreach to provide her with these medications on the street, even though she had identified that this would assist her with adherence to therapy. Neither the pharmacy nor her housing unit at the time were particularly close to where she was generally allowed to deal from, and because she wasn’t high up on the chain of dealers, she had to work when she was told, usually overnight. She’d then be too tired to walk home and subsequently miss the dose. Without staff who were able to do medication outreach, she simply stopped taking them. In the mainstream health-oriented world, this dilemma would be taken as evidence that Missy was not being “engaged” in care or not adequately prioritizing health.
Likewise, being out of the informal economy because of an extended hospital stay meant that there were costs in terms of her ability to survive in the downtown community when it was the case that she would have to return there when her time in hospital was over. Dealing in hospital meant potential incarceration and certainly the wrath of the health care professionals, but leaving hospital for a day at a time to contend with “business” meant getting a reputation for AMA’ing. Knowing that her belongings would have been moved from her room to the hallway of the hospital after being gone for twelve hours made it difficult to want to return. She would also receive knowing looks from the staff, comments about her being off the ward, and have to re-negotiate a bed with promises that she would stay; these promises were often difficult to keep, given the survival struggles previously described. Her reputation in one world as a good worker meant sacrificing her reputation in a different world. She was a difficult patient.

The dynamics of dealing, and Missy’s need to remain within a position where she could mobilize resources either from other community members or from dealers higher up from her, might be taken as either irrelevant to carrying out health actions or as inherently problematic because of their illicit status. But it is imperative to take into account the ways in which the oppositional relationship between drug use and following through on health (and the identities attached to these actions) are in fact constructions. There are competing ideologies at work, but both of these naturalize the consequences of drug use and drug dealing, making it difficult to see how such consequences are heavily constructed and “predictable” for those who are unable to mobilize resources to mitigate the social impact of illicit activities. As I have suggested, there is a tendency to prioritize the view from the health care/rational agency world, that people just shouldn’t be using or dealing drugs, and what happens to them as a result—ill health, poverty—are merely natural consequences. These presumptions are not unusual in highly stigmatized health and social circumstance (HIV infection, poverty) and reflect the ways in which the
conditions are thought to be reflective of moral character; liabilities and failings in health are personal failings, and illness is based on desert.

It is notable that this punitive view of illness was, not all that long ago, commonly attached to conditions such as cancer. We should recognize that the punitive view garners strength from the unexamined presumption that poverty or ill health are always consequences of drug use; rarely is the reverse argument advanced, that ill health and poverty are the reasons for drug use (Culhane 2003, 596). The contrasting view, that addiction is a chronic relapsing and remitting illness appropriately located within the medical domain, is meant to step away from the punitive view of addiction. But it too functions to depict ill health as a natural outcome of drug use. The competing condemnatory and medicalizing discourses generate similar effects.

Despite the fact that it is illogical and discriminatory to refuse treatment to individuals on the basis of what is now deemed to be a medical condition, it is nonetheless unsurprising that the punitive view makes its way into health care encounters quite easily. Not for all practitioners of course; many do recognize that taking a punitive approach to drug users’ health contravenes their ethical orientation to practice, particularly those who profess a commitment to trying to extend the benefits of the health care system to those who are most often disenfranchised from it. But the punitive perspective is also widely recognized to exist, as the earlier interview with the HIV home care nurses suggests. This perspective also seems to presume that other sorts of judgments or discriminatory attitudes (e.g. discriminatory attitudes toward certain ethnic groups, toward the urban poor) are not also comingled with the attitude that people just shouldn’t be using drugs, or at least not doing so in a way that is apparent to all those who have to contend with them. Drug use happens, as a number of researchers have pointed out, all over Vancouver—it’s only a problem for health care service use when the users are poor, non-White, and residents of a highly visible and much maligned community (Robertson and Culhane 2003). In those instances, individuals are already under public scrutiny and likely to have difficulties within the health care
They also often have fewer opportunities for an adequate legal source of income—all social determinants of health that are above and beyond whether or not they use drugs.

These issues should be understood to problematize the “common sense” view that roadblocks to drug users’ health are always and simply of their own making. As a case-in-point, we might reflect on the observation that there are other individuals from the inner city community for whom drug use and adherence are compatible—they have other resources and social supports mobilized around them that help to make this happen. Pink and Tina, whom I have previously introduced, are two such individuals. Pink, in particular, has numerous health complications including limited mobility, chronic obstructive pulmonary disease, and seizures; she takes more than twenty-seven pills, twice each day. In spite of on-going crack use, she has done very well on her antiretrovirals, is very adherent to therapy, and has a good relationship with the home care nurses who provide logistical and emotional support to her on a daily basis. Her nurses often have to argue with their managers and other team members that she should be kept in the home care program; with their support though, she does very well. The lack of straightforward paths and the overabundance of circuitous ones are outcomes of a health care system that sets expectations based on the norms of selfhood and rational autonomous agency and envisions the survival strategies and experiences of those who are systematically disadvantaged as transgressive and deviant. Thus the disunity of identity and the problematic movement from intention to action is a result of the exclusionary logic of self|other, and not an inevitable, immutable, or natural fact of the matter about a particular kind of person.

When spaces such as health care settings make one’s daily tasks incommensurable with the expectations of the institution, it is increasingly difficult to get on well in the system and with those health care providers who fail to see how their expectations of rational behaviour diverge from the ways in which women are able to navigate and survive in their other social locations. The contextual features of previous interactions in the medical system spill over into those that
subsequently take place. Take, for example, Missy’s abrupt departure from the hospital setting during the times that she felt she was treated badly while not receiving methadone for her opiate withdrawal, or what Carly called her “normal” response to an intolerable situation in a medical setting—to say “fuck it” and leave. These actions were frequent amongst the women that I worked with, when the combination of logistical and psychological roadblocks and the problems with continually acquiescing to the health care system mounted. They ought not to be brushed off as the childish reactions of disordered personalities. The difficulties contending with the navigation of inhospitable and hostile spaces generate the conditions that make non-adherence as reasonable a “choice” as acquiescing to the demands of the system.

In an extension of Scheman’s analysis of the possibilities for those whose identities are less seamless, less coherent and less solid than those of privilege, I now turn to examine what actions are available to individuals whose personal identities belie the norms of unmediated, straightforward agency when it is the case that the alternative routes and circuitous paths are impassable. Scheman’s analysis of identities that are representative of the norm (i.e. the “centre”) versus those that are marginal or “other,” does an exemplary job of demonstrating how those identities that are nearest the centre are often so taken-for-granted that they are unable to see the social apparatuses that can serve as collaborations or as roadblocks to agency, or how diverse forces might cause certain marginal identities to be pushed and pulled in different directions (Scheman 1997, 134). But we also need a better understanding of how it is that those who are ascribed marginal identities (ones she identifies as queer in various ways) often do not achieve the ends they might have, even for all of their circuitous navigation; we need a better picture of how marginality and disadvantage are perpetuated and social apparatuses, which prove problematic for some but invisible for others, maintained.
NEGATIVE AGENCY AND WITHDRAWAL FROM CARE

Drawing together the various issues I’ve been considering—epistemic injustice, the disparate meanings attached to receiving HIV/AIDS care, the ways in which ascribed identities and populist imagery function within health care—I suggest that we begin to think of non-adherence as a particular mode of agency. Appropriating the term “negative agency,” as used by Wardlow and Kratz, I extend Scheman’s discussion of agency by arguing that withdrawing from the health field is one way that agency can be exerted under conditions of diminished control and relationships that are structured by a generic universal ideal. Non-adherence to ART, stopping substitution therapy for addictions, and self-discharge from hospital stays, for example, can be read as the ultimate response to the difficulties of navigating a circuitous route to health.

Negative agency often confirms the very images and figurations that Scheman identifies as being attached to those who are unable to move easily and straightforwardly in society, and upholds the priority of place that dominant norms and social apparatuses have, maintaining the marginality of those who do not travel effortlessly on the roads marked by such structures.

Holly Wardlow takes up the notion of negative agency from Corrine Kratz, whose study of Kenyan Okiek marriage arrangements has led to her development of the concept as a way to conceptualize structurally limited courses of action (Wardlow 2004, 72). The term “negative” stems from a number of aspects of the field study: within the marriage arrangement, a bride has only the ability to choose to cooperate with the arrangements being made or to refuse participation. When she does what is laid out for her, she cedes agency to her new husband; in the latter case, refusing to participate is seen as oppositional, which sets her apart from the community and leaves her maligned by her elders, while also continuing to lack adult status (Kratz 2000, 138-146). The negativity of the act comes from the adverse effects of her resistance and the inability in this setting to recognize her actions as a self-defensive protest (Kratz 2000, 146). Wardlow extends the use of the concept in her own work in Melanesia. She uses it to
denote a variety of circumstances where women’s options for agency are restricted and they respond to this restriction by withdrawing their productive energies from the social field altogether (Wardlow 2004, 72-73). A woman might “forget” or “misunderstand” the instructions of her husband, thwarting the plans that relied on her cooperation (ibid); at an extreme end, she might remove herself from the social field and from productive activities through self-harm, including the amputation of a digit as well as suicide (75-76). Such actions have symbolic as well as practical and material effects.

Wardlow’s deployment of the concept indicates, first, that it is possible to extend an understanding of negative agency outside of the field site in which it was developed. This is significant, as it is the case that I am conceptualizing a very different set of practices and actions using the same concept. For Wardlow, negative agency is a marked departure from the “usual” (i.e. socially validated) forms that women’s agency take—women’s actions are described as being encompassed by men and geared toward social productivity. Negative agency is therefore a mode of agency in which women remove their productive capacities, skills and energies from the social group and undertake actions that are refusals to cooperate or to be encompassed.

There are obvious dissimilarities in the actions I am considering—by and large, I am not looking at actions or events that are about productivity or social cooperation in the way that Wardlow means to discuss. Of course, a substantial component of the underlying social anxieties about drug users and about their utilization of health care services is that they are not seen to be contributing members of society and that their actions generate expenditures, particularly when they remove themselves from care and subsequently incur more significant morbidity (and health expenses) further down the line. The spatialization of HIV/AIDS within the inner city is argued, for instance, to invoke notions of “dangerousness” and activate neoliberal stereotypes of personal culpability and non-productivity (Robertson 2007, 534). The images of dangerousness and the issues of health expenditures are major aspects of the
motivation to ensure that drug users are adherent to therapy, and that as many as possible are engaged in treatment. But removing one’s productive capacities is not, *per se*, of explanatory value in cases of withdrawing from the health care field.

My own use of the term shares the same tone as Wardlow’s. The parallel is in the way that withdrawing from a specific field of activity is an agentic move, one that is often very destructive and carried out because of a lack of palatable alternatives and not merely the absence or a failure of agency. The connection Wardlow draws between negative agency and self-harm emphasizes just how destructive negative agency can be, and how this mode of agency is undertaken when one has few legitimate or recognized means of protest. Thus in my own setting, it is not insignificant that women withdrew from medical settings when they felt they were treated with an utter lack of regard and also when their assertions concerning their experiences, most often of pain or withdrawal, were met with skepticism or derision. On those particular issues, the ascribed identity “drug user” removed the basis for other routes of action, which rely on being seen as someone who is credible and who is able to effectively speak and make claims within that space.

At a more general level there is another likeness to Wardlow and Kratz’ use of the term. Negative agency, in each of our uses of it, is seen as opposition to the normative view of agency in that setting and its actors maligned and marginalized from the social field through its enactment. In the clinical settings I’m considering, “forgetting” about an appointment that is likely to lead to a hospital admission or an unwanted procedure, or pulling out an IV line and angrily departing because of a derogatory comment, are respectively understood as contrary to rational autonomous agency. In the first instance, the individual is passive, rather than an active, self-determining agent; in the second instance, their actions are received as irrational (driven by addiction or being “childish” or impulsive) as well as irresponsible. On the conventional liberal account, consistent passivity with respect to important ends and conceptions of the good,
irrationality, and irresponsibility are all taken as indicative that one has failed to achieve the standards of autonomous agency; actions that I’m taking to be indicative of negative agency are actions that, like its actors, are understood to deviate from the norm. If negative agency appears to be a pejorative and nihilistic depiction of a mode of agency available to certain individuals, it is because the images and figurations of drug users and non-ideal Others that structure what actions are possible for those who perform this mode of agency are themselves pejorative and nihilistic representations. Actions are destructive at least in part because the structural arrangements and roadblocks that are thrown up along the circuitous path to “health” are also destructive, albeit often in ways that are difficult for those impacted by them to identify. These arrangements are not always instantiations of economic exploitation or legal inequality, or other forms of oppression that are more apparent to wider society and with formal (even if not always effective) means of recourse. More often and more pernicious, the roadblocks we need to worry about are psychological forms of oppression. Logistical challenges in health care services, by setting the stage for negative agency, lead to a reinforcement of the notion that the individuals who are unable to contend with them are somehow inferior and/or transgressive. If the “fuck you, I’ll show you a binge” that I’ve argued to be distinctive of negative agency reinforces stereotypes and pejorative images of drug users as irrational, it is less a reflection of a bad or destructive character and more a mapping of the effects of the domination and exclusion of difference.

THE LIBERAL TRADITION’S REBUTTAL

Contending with issues of inequality and social exclusion, the strategy of liberal accounts has been to attempt to simply extend the benefits of privileged social positioning to marginalized
others, arguing that liberal tenets do not, in principle, entail the exclusion of others; the ideals of selfhood are argued by liberals to be unproblematic as a standard for personhood and agency (Scheman 1997, 131). In contrast, feminists have critiqued the universalist ideals of liberalism on the grounds that the liberal view of the self is an individualist, masculinized self, based on the standard experiences of those in positions of epistemic, social, and economic privilege. Diana Meyers, for example, argues that because the liberal humanist response to inequality remains committed to impartial reasoning, past injustices may be reinforced and the presumption made that the interests of the excluded can be assimilated to those of the dominant group. This approach is argued by feminists to negate difference and thwart moral recognition of diversity (Meyers 1994, 6). In her characteristic prose, Luce Irigaray explains:

> To make the Black equal to the White, the woman equal to the man, is still to submit them, under cover of paternalist generosity, to models put in place by Western man, who resists living together with the different. (Irigaray 2004, 25)

Insofar as the liberal aims of tolerating difference and striving to treat all as equal keep in place a unitary rational self as its reference standard, the modes of agency available to those whose social identities are constructed as different are still circumscribed by the norm.

In philosophical writings spanning more than fifteen years, Cass Sunstein gives what I take to be a sophisticated and comprehensive liberal reply to the feminist challenges as depicted above. Sunstein attempts to rescue the model of rational agency from the obvious observations that agents are imperfectly rational and that social norms and values inevitably influence their reasoning processes. His endorsement of the liberal project reflects both his understanding of the importance of liberalism in principle and his view that liberalism is in fact able to attend to the impact of social norms and social roles in shaping possibilities for human agency. On his account, liberals must shift away from an argument to protect peoples’ stated preferences and agree to consider the role that background conditions play in the determination of said preferences.
Arguing that deliberative democracies ought not to respect or protect private preferences formed on the basis of unjust social conditions, Sunstein places the criteria of welfare and autonomy as ultimately higher than that of preference satisfaction (1991, 10). Sunstein writes:

The notion of autonomy should refer instead to decisions reached with a full and vivid awareness of available opportunities, with reference to all relevant information, and without illegitimate or excessive constraints on the process of preference formation. When these conditions are not met, decisions should be described as unfree or nonautonomous; for this reason it is most difficult to identify autonomy with preference satisfaction... For purposes of autonomy, then, governmental interference with existing desires may be justified because of problems in the origins of those desires. (Sunstein 1991, 11-12)

The ideal of autonomy that Sunstein describes is of rational autonomous agency—he is focused on decisions (i.e. intentions) that are formed with adequate information and without undue manipulation, coercion or constraint. In contrast to other liberal theorists though, Sunstein makes clear that “preference” doesn’t capture this social-historical context within which choice exists (Sunstein 1991). He writes that individual rationality and choices are both functions of social norms, social meanings, and social roles, which individuals may approve or deplore, and over which few (if any) individuals have control. “What is rational for an agent is a function of, and mediated by, social roles and associated norms” (Sunstein 1995, 9). The expressive meaning of an act, says Sunstein, is an important aspect of choice, and it is not up to the individual to determine (7).

In view of Sunstein’s position on norms and roles, it follows on his account that rational autonomous agency is only possible in societies where there are social norms that endorse a variety of possible conceptions of the good (1995, 7) or where norms that shape inequalities (e.g. racialized norms) are the object of social policy and change. For Sunstein, the liberal conception must be concerned with preference formation and not just its satisfaction—the information, consumption patterns, social pressures, and rules that direct the formation of preference (the attitudes underlying intentional actions) are the rightful domain of a deliberative democracy.
Autonomous agency is an _ideal_, which agents may not achieve, but as his view suggests, this is a justifiable matter of governmental interference.

Sunstein’s work can be taken as a response to the feminist critique on two fronts: first, inasmuch as he argues that liberal conceptions of agency are _not_ merely about rationality and individual freedom, and that choice is not as straightforward as it is sometimes taken to be, he directly refutes the concerns of feminists who argue that traditional liberal philosophy fails to acknowledge structural forms of inequality and historical disadvantage (Sunstein 1995, 4). Second, Sunstein can be taken as responding to the critique that liberalism does not _address_ systemic forms of oppression and subordination, through his exploration of whether a defensible liberal democracy might be able to override the private beliefs and preferences of its citizens, “not in spite of its salutary liberalism, but because of it” (Sunstein 1991, 4). In the second instance, Sunstein is particularly concerned to demonstrate that liberal philosophical approaches to rational autonomous agency _can and must_ alter unjust background conditions or the choices that stem from them. He explicitly argues that it is appropriate for the law to intervene and alter norms that are inimical to well-being, for example, discouraging addictive behaviour or the consumption of dangerous drugs (Sunstein 1991, 11; 1995, 7). To achieve such ends, government might try to inculcate or diminish fear or shame surrounding particular social practices (1995, 8).

What could Sunstein’s approach do to counter the sorts of worries raised by my analysis of the place that liberal humanism has within HIV/AIDS research and care? At a very basic level, his view suggests that social norms and roles shape _all_ preferences and actions, not just those belonging to individuals and groups construed as outside the bounds of rationality. A certain kind of democratizing of _irrationality_ is going on here—_all_ humans, Sunstein says in various places, are influenced by norms, systematically err in their assessments, and make choices that are not in their best interests (Sunstein 1995; Thaler and Sunstein 2008, 9-11). This
could arguably prevent Sunstein’s approach from going the way of other liberal theories, which pit universal standards against those of the “Other,” generating an economy of the same. More concretely, Sunstein gives instances in which there might be justifiable intervention (private or state) to prevent certain forms of objective harms. The norms Sunstein has in mind in particular are those that are obstacles to human autonomy (e.g. norms discouraging certain groups of people from becoming educated) or harmful to well-being (as in norms related to dangerous drugs). For certain activities such as drug use, trying to influence social norms to proscribe drug use is not enough—risks also need to be regulated. Sunstein writes, “If Nancy Reagan tells teenagers to “just say no” to drugs, many teenagers may think that it is very good to say “yes” (Sunstein 1995, 14). By having the substances illicit and by limiting access to them, Sunstein argues that governments create policies that regulate social norms and generate new ones, which might operate to save lives and improve well-being.

A RESPONSE FROM THE MARGINS

I have no misgivings about Sunstein’s concern for preference formation—in that respect, his philosophical position is an important and welcome addition to the liberal tradition. And on the face of it, there is an affinity between Sunstein’s discussion and feminist worries regarding background conditions and the social-historical context of “choice.” In spite of this, I will argue that Sunstein does not adequately address what is so problematic about institutional presumptions of rational autonomous agency. This argument breaks down into two sets of considerations: first, there are specific elements in Sunstein’s approach that are objectionable on the grounds I have been staking out over the course of this project; second, at a more abstract level, there are problems with the formal aspects of Sunstein’s approach. My overarching concern, which unites the two arms of my argument, is that rather than see liberal ideals of autonomous agency and the self-as-rational-agent as contributing to the challenges of agency for
members of socially disadvantaged groups, Sunstein’s approach leaves in place the idealized self and rational autonomous agency as privileged concepts.  

With respect to the specific content of his position, it is clear that when Sunstein does argue that systems of inequality can be targeted through changes in law and social policy that alter social norms, he is not talking about norms that place the liberal humanist view of the self as the pinnacle of humanity and rational agency as central to autonomy. Consider Sunstein’s view in *Nudge*, a monograph jointly written with Richard Thaler. In the introductory pages, Sunstein and Thaler argue that governments and private organizations ought to “steer” people’s choices when information regarding what the best of those choices would be is available. Declaring a role for so-called “choice architects,” they argue their position on the grounds that people do not actually act fully rationally—with full attention, information and self-control—but that if they were able to do this, they would, and moreover, would agree with the outcomes of such steered choices as being in their best interests (Sunstein and Thaler 2008, 5).  

Setting aside some obvious concerns about elitism and the designs of philosopher kings, we very clearly have the picture of an ideal self. The authors go so far as to call this ideal human an “econ,” as in, *homo economicus*. The problems arise when people diverge from this. The rational autonomous man still holds the position of a character ideal in this account.

There is absolutely no consideration that, perhaps, the norms of an ideal rational self or of rational agency are part of the problem of injustice and inequality. He certainly believes there to be necessary constraints on government interference, identifying these as being denoted by “rights” in common vernacular and expressing particular concern for the protection of those rights that increase overall autonomy, citing such things as minority rights and the right to freedom from sexual coercion (Sunstein 1991, 13). But we need also to notice how “rights” talk keeps us locked into a humanist view of the idealized subject as unified, self-reliant and autonomous (Code 2006, 201-203). And again, Scheman is helpful here: those who think in
privileged ways seem to envision their thoughts as being valid and appropriate for the rest of us; the modern (liberal) basis for this claim is that there is, in fact, a “best,” most normal and healthy way to be (Scheman 1997, 129-130). Suggesting that there should be numerous and widely available conceptions of the good won’t deal with this criticism—particular “ways of being” (e.g. being addicted to heroin) are set up to look like lifestyle choices that are objectively “bad” and need correction, rather than being understood as a wide-ranging and heterogeneous set of phenomena.

Substance abuse and its consequences are very often entangled with economic, social and historical conditions of disadvantage, as well as the social response to actions that are purportedly in opposition to norms of rationality; this is arguably not an issue of lifestyles at all. Sunstein fails to adequately address this point in his analysis, a problem that is compounded by his enlisting of the distinction between “belief” and “fact,” a distinction that I note to be one aspect of colonial frameworks of difference.20 In contrast to the “beliefs” of often fallible and irrational humans, the facts are out there, ready to be uncovered and rationally acted upon, once the lens of the “social” is improved upon. This is presumably why he argues for choice architects and norm entrepreneurs—individuals and collective bodies who can steer us away from bad choices and faulty beliefs.

This language of fact, lifestyle and choice architecture reflects how medicine, addiction medicine in particular, can be understood as part of a modern project of self-actualization (see Keane 2000). Foucault describes “technologies of the self” as historically and culturally specific ways in which subjectivity is constituted (rather than being a transcendental feature of humans), which:

permit individuals by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct and ways of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality. (Foucault 1988, 18)
Technologies of the self interlock with more obvious forms of disciplinary power, which are likely to be mobilized when consciousness projects do not adequately engage certain individuals or groups, who are then seen as deviant and transgressive. But this relationship is obscured by the presumption of the universality of reason and the lack of appreciation of the way in which “facts,” along with ways of thinking about the world, are cultural and historical moments. Thus the emphasis on self-actualization and the engagement of consciousness is all the more dangerous from a position such as Sunstein’s. It is also reflective of a deeper problem within liberal philosophy more generally—there’s very little appreciation for the ways in which subjectivity is always formed within and through power, even when it is productive or positive.21

Sunstein suggests that maintaining the freedom to choose “bad” decisions will be the best safeguarded against potentially inept designs by choice architects, which are not so much a problem because of worries of elitism and designations of epistemic authority or credibility but largely related to incomplete information (Sunstein 2008, 11). First, this misses the mark with respect to the worry about self-technologies and their relationship to disciplinary and repressive forms of power. Second, this framing does not recognize that the construction of choice very often leaves systems of privilege in place. Thus the “choices” of privilege are unlikely to be seen as problematic, while the supposed badness of other “choices” for those who are disadvantaged will remain imagistically opposed to the standards of privilege.

The freedom to choose “badly” reflects how Sunstein’s view seems to assimilate claims about the availability and use of illicit drugs with the issue of being addicted to them under the generic problem of certain drugs being a “bad” choice that public policy ought to discourage. This brings us to the problematic formal aspects of Sunstein’s position. For as much as I agree that government policies and law need to address historical and social background conditions such as racism and poverty, attempts to cope with inequality through social norms and roles will be impotent so long as problematic aspects of liberalism remain in place. In order to appreciate
this problem, we need to understand how it is that Sunstein maintains a liberal account of rational agency and the self-as-rational-agent as an ideal. He argues throughout *Preferences and Politics* that it will not do for a liberal democracy to accept preferences as given or as fixed, and that not all preferences can be put on the same plane (10). There must be autonomy, he argues, within the development of preferences (“wants”) and not just in their satisfaction (12). Likewise in *Social Norms and Social Roles*, he makes it very clear that he is concerned with social norms and social roles that undermine citizens’ abilities to choose reflectively and deliberately between reasonably good options (Sunstein 1995, 40). In both of these papers, respect is due only for some kinds of preferences, those that are not “deformed” by unjust social conditions.

For as much as he recognizes that social life is not possible (or imaginable) without social norms (Sunstein 1995, 13), there is a tacit presumption that certain individuals, in positions of privilege, have preferences that are un-deformed and hence are properly autonomous. Likewise, he suggests that it is possible to alter or reject norms through reflective judgments (ibid), though he does not actually give an account of how critical reflective judgment is possible, given the pervasiveness of social norms and roles. We are left to suppose that some people are able to transcend the socialization process. Ultimately, the discussions in each of these works is directed toward organizing society so as to pull all those who sit outside the realm of privilege into the putative centre, enacting what Scheman refers to as “democratizing privilege” (Scheman 1993; cited in Scheman 1997, 130). Sunstein does argue that the collective will of the majority may be mistaken about norms, thus when defining who they are and what their values require, the “wants” must be supported by reasons (Sunstein 1991, 13). But as my first set of concerns articulated, there is no attention to whether “reasons” might not be as timeless and universal as they are presumed to be.

The need to change oppressive social norms is a fine point to argue when it is the case that the norms in question are relatively easy to identify as problematic for some and likely to
perpetuate historical patterns of disadvantage. It seems straightforward to argue as Sunstein does, that the meanings associated with educational achievement amongst certain racialized groups are problematic, for example, that being successful in school is being “white,” where this characterization is treated as derogatory. Society might therefore be justified in intervening against such norms if they undermine educational achievement. Using the terms that Sunstein supplies, we would say that uncritically partaking in this social norm is detrimental to overall autonomy and welfare of group members and likely to deform preferences. But it is not always so straightforward to determine whether a social norm might be nudging people in the direction of greater welfare (or autonomy) or whether the norms in question are part of the problem.

Take the role that social norms play in stigmatizing sex work—one might think that these norms (helpfully) dissuade people from entering forms of work that are stigmatized as demeaning and alienating; the stigma might also be helpful in maintaining a separation between spheres where it is appropriate to interact with individuals based on a desire to use their sexual capacities (private sphere, with consent) versus social locations where this is unacceptable (public sphere). In a compelling discussion of the norms associated with legal restrictions on prostitution, Martha Nussbaum compares sex work with other forms of bodily labour and argues that the negative social meanings attached to taking pay for the use of the body are a reflection of class privilege and fear of the (woman’s) body. To paraphrase Nussbaum, stigmatization may be well founded, based on convincing well-reasoned arguments. But it may also be based on class prejudice, or stereotypes of race or gender (Nussbaum 1999, 276). This cannot be determined simply by examining descriptions of the practice in question and determining whether the description is accurate or correct. A “factual” account of the social meaning of a practice doesn’t offer anything about its historical context, for example. It “is therefore just a door that opens onto the large arena of moral and legal evaluation” (Nussbaum 1999, 277). There needs to be more said in order to determine whether current beliefs are from reason or prejudice. The
trouble with Sunstein’s position, a point which I argue more forcefully below, is that his examples seem to presume it will be quite obvious which is which, and that the well-reasoned arguments are not themselves tinged by forms of prejudice that are widely taken for granted in liberal democracies.

Furthermore, when we take into account my arguments detailing how liberal idealizations of the self and rational agency are part of the problem of non-adherence to ART, Sunstein’s position becomes even more untenable. The forms of difference that Sunstein is prepared to embrace, through divergent conceptions of the good, are those that do not appear to violate the liberal conception of the person—what Diana Meyers has pointed out to be a singular model of personhood that only makes room for superficial and accidental forms of difference (Meyers 1994, 24, 26). The views that Sunstein holds, of the self and of agency, are also norms; I have argued that they have a role to play in policing the boundaries of marginality. But Sunstein does not seem to want to give up on these norms. Nor does it seem possible that his account would be able to consider how they might themselves be problematic, because he is arguing that they are the appropriate standard of comparison, and would be achievable were it not for the lamentable social conditions of those who do not yet meet this standard. His argument is focused on how we might alter the social conditions to help everyone achieve the liberal norms, rather than seeing the liberal norms as part of what delineates and maintains marginal social groupings.

This is precisely the worry that Irigaray raises in the earlier citation. And as Scheman is quick to point out, employing the exclusionary logic of identity, what is taken as “normal” actually depends on the presence of an abject other to maintain the definition of the centre (Scheman 1997, 128). Those who cannot meet the demands of sameness are continually pushed to the margins. As my discussion of Lugones and Scheman has touched on, the possibility of an unmediated route from intention to action by a solid, transparent self is one that is dependent on a compliant social structure and a privileged social identity (Lugones 1990; Scheman 1997, 125-
While it seems that Sunstein could agree with this thought generally, he does not consider how those who do not share in the distribution of social and economic privilege have different modes of agency available to them as a result of their positioning and often experience themselves in ways other than those given by the transparent, unified, rational ideal of the liberal account of the self.

A liberal response to these worries might suggest that distinctions between objectively better and worse ways of living are not only possible, they are currently accepted by even those who end up living “worse” lives. One might argue that most people with addictions, for example, do not think of their lives as being “better” because of those addictions than they would be without them and at least attempt to get out of their problematic circumstances. We see this sort of position in a number of articles where Sunstein argues for the legitimacy and appropriateness of a government’s use of shame and fear to deter its citizens from illicit drug use, “preferences,” or “wants” that he takes to be objectively harmful.

Sunstein himself acknowledges the problems with anti-drug campaigns directed toward current non-drug users; he fails, though, to recognize that at a very basic level, much of what is harmful about on-going drug use is tied to the fact that it is illicit and not to the chemical nature of the substance in particular (though this might be said to differ depending on the drug). This harm is the point of government policy, but it generates the harmful conditions that the policy is supposed to be preventing.23 The framing of the “drug problem” in North America has generated images taken up by middle and upper classes, that “tough on crime” policy measures are necessary even though they have little to no effect on the amount of drugs available on the street (Johns 1992); the policies do distort images of who drug users are and their danger to society. “Recreational” drug users are often not often considered the subjects of such policies, or even imaged as drug users, while the racialized tropes of crack babies, welfare queens and dangerous gang members abound. The well-articulated critiques of the internal “war on drugs”
policies such as three-strikes laws have likewise documented how the legal sanctions are often in gross disproportion to the gravity of the offenses and reflect the perceived dangerousness of the offender (a perception that is reinforced by the patterns of sentencing themselves).

Consider, for example, that crack cocaine is punished in the U.S. much more severely than powder cocaine. The use of the two forms of cocaine is thought to divide along racialized lines, with the burden of severe penalties falling on African Americans, including the use of disenfranchisement, i.e. ineligibility to vote (Fletcher 1999). When they are enacted, drug policies help to racialize crime statistics, criminalize poverty, and perpetuate patterns of civil injustice. The challenge with suggesting that policies can simply be “evaluated” to see if they are working, and altered if they are not, is that a set of values that are decidedly problematic for particular social groups has been universalized, and it can be exceedingly difficult to see exactly how the policies themselves are troublesome, and the patterns of disadvantage they produce contingent on values that underpin the policies themselves. The alteration of pejorative figurations and images, and their use in framing decisions such as sentencing, are not always or often available for straightforward reflection—culturally normative prejudices are part of the corpus of “common sense” in such a way that they are often embedded in the unconscious of even those who see themselves as unbiased and egalitarian and interlock with other prejudicial figurations in such a way that the refutation of one results in the assertion of another, such that they are impervious to criticism (Meyers 1994, 51-56).

Sunstein’s view relies on background assumptions that presume drug use is bad and should not be rationally engaged in. Because they are deemed to lack the capacity for rational self-governance, authoritarian control of “addicts” becomes the logical consequence of a commitment to liberal ideals (Bull 2008, 153; cited in Keane 2009, 451). But as my discussion above and work throughout this project argues, drug use is particularly “bad” and indicative of irrationality for certain socially and economically disadvantaged groups, and often for reasons
related to the policies generated around drug use. Middle and upper class drug users are simply “recreational” users, not addicts. Moreover, as my discussion in Chapter Four indicates, much of what is challenging with carrying through on health care is very closely connected to the shame and fear that is already generated in society around the use of illicit drugs. Yes, norms shape the possibilities for action—I have been arguing as much throughout. But as my empirical work has demonstrated, for women who fall on the exclusionary side of a given norm, their actions are constrained in such a way that their marginal positioning is maintained, and the negative consequences of social norms and social role further trouble the possibilities for their lives.

This is not a relativist argument that we cannot judge whether a person’s way of life is good or bad for them, and on-going substance abuse is just one “way of living.” I have argued throughout this project that the view of addiction as a “lifestyle choice” is itself part of a liberal social imaginary, and should not determine public policy.24 My point is that while certain components of Sunstein’s position are presented as “objective,” they are not value neutral. Certain values need to be endorsed in order to accept his critique of values and norms that he argues to diminish autonomy. As such, his account produces the same centering of privilege as does the liberal tradition he attempts to improve on; the privileged norms are amongst the forces that police the boundaries of marginality. An adequate examination and critique of social norms and ideals (those that seem problematic as well as those that seem beyond reproach) cannot be given from a position that ignores the way in which “facts,” by being presented as universal and timeless, carve out positions of social superiority that are often based on underlying racial and class distinctions. We need also to be able to ask what it is that norms and ideals do for people who are differently positioned in society—and not simply go about throwing out or changing the “bad” ones and generating “good” ones.
CONCLUDING REMARKS: AGENCY, STRUCTURE AND CONDITIONS OF POSSIBILITY

This chapter has drawn on the meanings that are attached to health care encounters, and the ways in which women’s day-to-day lives in Vancouver’s inner city can make norms associated with rational autonomous agency impossible to achieve. The problems with rational autonomous agency are not simply that certain individuals have trouble achieving it, or that certain historical and social background conditions make it difficult for some but not others. My examination of negative agency suggests that it will not suffice to ground considerations of how women negotiate, accept, and sometimes resist HIV care on a primordial rational “self,” nor to view women’s actions in and outside of the health care system as demonstrative of authentic identity. Challenges within the health care system are linked to agency and social identity by way of the taken-for-granted aspects of the self along with determinations of what constitutes reasonableness and facts-of-the-matter.

A different view of the self and of autonomy is needed. This account must dislodge the taken-for-granted aspects of the contemporary landscape of moral and political liberal philosophy, while also appreciating the influence of systemic forms of inequality. Describing non-adherence to ART as a form of agency that is available to those who are held as oppositional to an ideal liberal subject gives a different picture of the contours of agency—one that takes self-identity (even in its ideal forms) as relational, multiple and fluid, rather than individual, cognitive and bounded. This description will be the foundation for an alternate account of agency, autonomy and the self that is relational the whole way through.
CHAPTER SEVEN
RECONFIGURING AUTONOMY

“No politics without identity, but no identity which takes itself at its word”
(Jacqueline Rose 1986, 157)

If we are solely aimed at bringing as many as we can into the liberal-conceived status of autonomous agency, those constructed as the antithesis of unified transcendental identities of privilege will continue to be regarded as marginal. My empirical research has, by this point, made clear why we ought to be concerned about the potential for constructing certain social identities as pathological in comparison to an unstated, apparently neutral norm. Traditional liberal views help to perpetuate the marginality of those whose differences cannot be reconciled to fit some version of the ideal of rational autonomous agency; we need, therefore, to find a way out of the framework established by liberal accounts while also re-conceiving autonomous agency in a manner that does not trap the subject in the exclusionary logic that I have argued stalks this tradition.

Such is the work of this chapter.¹ My account of the contours of agency within the health care system for patients whose ascribed identities are denigrated by traditional liberal ideals provides a segue into a reconfiguration of the concept of autonomy.² The problems of its liberal heritage aside, autonomous agency has an important place in moral and political philosophy (Mackenzie and Stoljar 2000); its application in the domains of medicine and bioethics are likewise significant (Sherwin 1998; Donchin 2001). Within medicine, autonomy is related to the establishment of informed choice and respect for persons. Ensuring a place for autonomy is a means to correct power imbalances between healthcare service providers and patients. Valuing autonomy also enables medical practice to occur within a society with highly pluralistic beliefs and values (Sherwin 1998). It is in light of these considerations that I offer a reconfiguration rather than a rejection of autonomy. A reconfigured account ought to give some indication of the
basis for mutual recognition; it ought to address issues of privilege and disadvantage; and it ought to establish a foundation for the respect of difference. If it cannot address many of these issues, which current contenders for a well-functioning account of autonomous agency claim to do, it must offer an alternate and equally topical set of considerations to attend to.

For liberal philosophy as well as for its feminist critics, autonomous agency is widely understood to relate to the capacity for self-determination as well as critical reflection in the face of norms, practices, and institutions (Mackenzie and Stoljar 2000, 3; Allen 2008, 2). This is perhaps one of its most significant functions and the contact point between liberalism and feminist theory. Traditional liberalism worries about dogmatism and freedom from undue interference in exercising personal choice. Feminists likewise worry about oppressive social conditions; they contend, for example, with concerns regarding the intersubjective dimensions of selfhood that shape agents’ social identities. It is paramount that a feminist account is able to explain how resistance to oppressive norms is possible, in light of issues such as dependency and social exclusion justified on the basis of non-compliance with dominant normative standards.

Given my emphasis on the role that pernicious tropes, figurations, and norms play in structuring women’s agency within the health care system, autonomy holds particular importance for my analysis of adherence to HIV/AIDS care. My empirical project also suggests that a reformulated account of autonomy must be able to make sense of what it means to speak and act according to one’s interests, and what must be in place to ensure that there are adequate imaginative, epistemic, and material spaces to enable this occurrence. In this final chapter, I explore the limits of liberalism and sketch a reformulated account of autonomy that is able to contend with the challenges raised by my research.

**AUTONOMY AND THE LIBERAL “SELF”**

Liberal accounts argue that the unique situation of individuals within a given social order justifies claims that liberalism offers a view of autonomous agency that is functionally and
morally superior to possible alternatives. Liberal philosophy’s commitment to methodological individualism is an organizing principle in four “domains” that I take to be paramount to its conceptualization of autonomy. Even amongst reformulated accounts of autonomy that reject methodological individualism (feminist or otherwise), these domains must be contended with if competing accounts are to have any pull as reconfigurations. The domains are as follows: (1) concerned with self-determination, liberal autonomy suggests that individuals capable of critical reflection are in a position to determine and advance their own best interests, and should be able to do so; (2) pluralistic societies require a public and equitable foundation for mutual recognition and respect for persons, which liberal autonomy establishes on the grounds that the capacities of individuals conceived of as autonomous (rationality, reflectiveness, and unification) are understood to be universal capacities that liberal societies work to engender; (3) liberal autonomy is able to make justifiable assignments of responsibility for actions, because responsibility seems to demand that individuals act voluntarily, rationally, competently, and for their own reasons, i.e., that they act autonomously; (4) freedom from bias, dogmatism, and general sophistry can also be promoted on the basis of a liberal autonomous self, given that this ideal self is capable of both objectivity and reflective judgments and has the courage to think for itself.

From each of these characteristics, we see an agent who is morally, politically, and epistemically autonomous. The widespread commitment to liberal autonomy (in contemporary philosophy and in medicine) has more to do with these purposes within a pluralistic democracy than it does any metaphysical suppositions. If a reconfiguration can adequately attend to the functions of autonomy, I take it that the mainstream liberal account will no longer have a claim to priority either on pragmatic or on principled grounds.

My concerns from the previous chapter, regarding Cass Sunstein’s account of liberal autonomy, suggest that a reformulation is crucially required. But the basis for my critique of the
view of the self and autonomy offered by liberalism is not as simple as the claim that the accounts are “individualistic.” As Marilyn Friedman argues in “Autonomy and Social Relationships: Rethinking the Feminist Critique,” a number of liberal accounts are consistent with the view that social relationships are central to the realization of autonomy, including relationships that involve dependence, nurturance, and care.  

Liberal philosophers such as Gerald Dworkin, John Christman, and Cass Sunstein have gone to great pains to establish that their accounts of personal autonomy are not overly individualist, hyper-rational, or impervious to issues of socialization, even for as much as they endorse methodological individualism. My previous discussion of Sunstein’s account of autonomous agency has set me in agreement with Friedman’s claim—that feminist and mainstream liberal accounts of autonomy converge on a number of points. Sunstein’s account recognizes the cogency of feminist thinking regarding the influence of social norms and social roles on autonomy. That said, liberal views still miss the mark when it comes to certain aspects of feminist critiques. Accordingly, the first task of this chapter is to interrogate the grounds upon which a feminist reconfiguration of autonomy might be differentiated from accounts given by liberal philosophy.

As Friedman suggests, a number of mainstream liberal conceptions of autonomy do attend to social conditions (e.g., treating them as “causally” necessary for autonomy) and cannot easily fall prey to charges of individualism. Nevertheless, there are problems with these views, which feminist reconfigurations of autonomy draw attention to. Even amongst liberal accounts that recognize the necessity of social relationships for the development and maintenance of one’s sense of oneself, these views of autonomous agency emphasize the importance of independently authoring one’s own values, desires, and preferences. The self that is depicted by liberal philosophy is ideally an unfettered author of his destiny and master of his soul (Weir 1996, 184). Liberal accounts certainly recognize that this is not the case for all (or even most) citizens, but their focus is on how to ensure that individuals are free from coercive or manipulative contexts.
that hinder this self-authoring. Liberal accounts are predominantly worried about those who fail to meet its *internal* criteria for autonomous agency—some agents achieve autonomy, some contingently fail, but in general, liberal accounts attempt to expand the boundaries of who might be capable of autonomy.

The problem, as I emphasized in the previous chapter, is that normative frameworks of liberalism only expand conceptualizations of autonomy according to *its own* internal distinctions. By rationalizing certain ways of engaging and acting within the world as legitimate and others as illegitimate, particular “Others” are excluded. Specifically, I was concerned to detail how those who are ascribed social identities that are associated with illegitimate modes of agency (e.g., negative agency) are often refused application of the concept of autonomy altogether. Systems of images and figurations that are applied to individuals seen as contrasting with liberal ideals of autonomy (e.g., being predictably and consistently irrational or irresponsible) have a tendency to place such individuals *outside* of the criteria for autonomous agency. Sunstein, for his part, wanted to challenge problematic norms and roles that often serve as external criteria for autonomy. In doing so, he seemed to suggest that it is possible for liberal philosophy to reshape the margins of society, expanding the borders of autonomy, as well as to have those who remain in the margins protected from their non-autonomy through the instituting of liberal values.

But consider my earlier critique of Sunstein: by focusing on freedom from *problematic* or *deforming* social norms that hamper the exercise of reason and choice, Sunstein implies that socialization is only problematic when objectively bad or harmful norms and roles are at stake. When he argues that with better information and closer attention it should be possible to reflectively alter problematic norms, Sunstein suggests that the process of reflection is somehow free of the sorts of structures and relationships that generate the worrisome norms themselves. I rejected Sunstein’s view on the grounds that it is insufficiently attentive to the normative framework it relies upon. For groups whose circumstances give them sets of options, desires,
practices, and understandings that are incompatible with liberal ideals of autonomous agency, such agents cannot simply bootstrap themselves into autonomous activity. Those whose decisions govern such agents (Sunstein’s “norm entrepreneurs,” “choice architects,” and representatives of the state) only conceive of these individuals as persons whose activities fail to count as autonomous, and for whom any benevolent intervention might be judged by welfarist criteria, but not by autonomy. One cannot harm the autonomy of individuals who are constituted as non-autonomous; one can only (perhaps) affect whether they become autonomous (by liberal standards) at some point in the future.

My empirical research indicates numerous problems with this view. In Chapter Five I argued that an exclusionary binary is implicated in the ways that women who are drug-using and non-adherent to ART are depicted as chaotic and irrational; their ascribed identities are constructed in opposition to normative standards of liberalism. Exclusionary categorizations premised on supposedly neutral liberal views, I argued, perpetuate pathologies and marginality. The idea of simply contesting “deforming” social norms and roles in order to bring abject others into the realm of liberal autonomy, as Sunstein is wont to do, is indefensible.

MOTIVATING A RECONFIGURATION OF AUTONOMY

One way that feminist theorists have attempted to reconfigure autonomy, and address challenges of the sort that I have been directing toward liberal views, has been to argue for “relational” reconfigurations of autonomous agency. Increasingly employed within feminist theory, and feminist bioethics in particular, so-called “relational” views of autonomy are not a singular conception. The various accounts that are arguably covered by this umbrella term share the conviction that persons are socially embedded and that identities, central to the notion of autonomous agency, are shaped by intersecting social determinants within the context of social relationships (Mackenzie and Stoljar 2000, 4). Marilyn Friedman distinguishes between two forms that “relational” accounts may take—causally versus constitutively relational:
Are social relationships merely causal conditions that are necessary to bring autonomy about but are external to autonomy proper, rather like sunshine causing plants to grow? Or are they somehow partly “constitutive” of autonomy? Put differently, is autonomy merely the (nonsocial) result of certain other social conditions, or is it inherently social in its very nature? (ibid)

Different accounts may agree that the achievement of autonomy depends on personal capacities that must be socialized, but they do not all understand autonomy to be constitutively or intrinsically social (Friedman 1997, 57). I use these two terms interchangeably here; similarly, what might be called a constitutively “relational” account will be interchangeable with the term constitutively “social.” It is amongst causally social accounts of autonomy that Friedman suggests there is substantial overlap between liberal and feminist views.

It seems that we might make some headway with an adequate reconfiguration of autonomy by employing intrinsically social accounts. On these formulations, relationality must be part of the understanding of what autonomous agency is. Looking at a variety of intrinsically social accounts, Friedman makes a distinction between the claim that autonomy is intrinsically social because human selves and self-identity are so, and the claim that, apart from the nature of the persons who realize it, autonomous agency is also a social trait or process.

On the first interpretation, autonomy is inherently relational because the “self” is relational. This understanding of relationality emphasizes that the capacity for autonomous agency depends on temporal and social dimensions of selfhood. For instance, the human capacity to reflect critically on normative standards (in the absence of coercion or manipulation), such that one subsequently has the ability to determine one’s actions in light of one’s own considered judgments, depends on relational dimensions of the self. This includes having opportunities for affiliations with others, and the developmental conditions necessary for self-discovery and self-definition (Mackenzie and Stoljar 2000, 24; Meyers 2000). Indeed, a number of feminist reconfigurations explicitly articulate that autonomy is relational because of its foundation on a relational account of the self (Donchin 2000; Brison 1997; Sherwin and Mcleod
2000; Nedelsky 1989). Much of this line of thought has been informed by Jennifer Nedelsky’s early work on relational accounts of autonomy; relatedness to others (and institutions) is a literal precondition for autonomy, and interdependence, moreover, is a constant component (Nedelsky 1989; my emphasis).

To have a constitutively relational account of autonomy based on a relational self means that the capacities deemed central to autonomous agency are understood to be developed through social interaction and exercised within systems of meanings, values, and modes of self-reflection that do not exist outside or transcendent of social practices (Friedman 2000, 40). Schools, families, health care systems—these are institutions and social locations that shape the very capacity for developing and exercising autonomy (Sherwin 1998, Dodds 2000). For feminist bioethics in particular, the relational view of the self has a strong theoretical presence.

As described above, Friedman also asks whether autonomy might be considered constitutively social in a second way. That is, whether autonomy can be thought of as social *per se* (Friedman 1997, 57). In this instance, the claim is that autonomy is a social trait or process, apart from the relational self-constitution of those who realize it. This claim states that autonomy is *itself* the capacity for a distinctive form of dialogical engagement (Friedman 2000, 41). Friedman notes that although she is unsure exactly what this could mean, this is the sort of issue that will set the stage for the next round of feminist explorations of autonomy (Friedman 1997, 57). I agree that Friedman is right in thinking this issue needs to be contended with by feminists, but by and large, the implications of this latter aspect of what it means to be intrinsically social are left out of a number of feminist relational accounts, in favour of explorations of a relational view of the self.

The obvious question is whether these intrinsically relational accounts provide the conceptual-theoretical resources to avoid the sorts of criticisms I have been directing toward liberal views of autonomy, which are arguably not so different from causally relational accounts.
My answer is an unsatisfying “maybe.” I will argue that intrinsically relational reconfigurations of autonomous agency have the potential to avoid the challenges I have raised to liberal accounts of autonomy. I say “potential” because I do not believe it is the case that all intrinsically relational accounts attempt to answer the challenges I have begun to lay out against liberal views. Margrit Shildrick shares my concern that even intrinsically relational accounts do not respond to the radical implications of the critique I have begun to articulate:

for all the refinement of existing concepts, nothing much appears to have changed. In particular, the concept of autonomy, which is central to liberal humanism in its masculinist formulations, gets kicked around a bit, only to reappear in revised forms that extend agency to previously oppressed groups—women, patients, global others—without any thoroughgoing inquiry into the efficacy of any formulation of autonomy as a privileged bioethical concept.

(Shildrick 2008, 32; original emphasis)

Shildrick suggests that the problem with many accounts is their inability to disengage from the image of a bounded subject who acts, consents and chooses as an individual (34). The profundity of Shildrick’s worry is apparent when we begin to consider a widespread tendency amongst both relational and liberal accounts to emphasizing how power relations are problematic for the development of autonomy, while simultaneously failing to heed the flip side of this issue—namely, how disciplinary and authoritative relations are implicated as much in achievements of autonomous agency as they are in the undermining of autonomy. It is this flip side that I employ in a more radical critique of liberal autonomy, which may equally apply to relational autonomy. I suggest, therefore, that one of the distinctive contributions an adequate relational account of autonomy can make to the theorizing and application of autonomy is to have symmetry in its analysis of autonomy, relations of power, and structure; interrogating achievements of autonomous agency just as it interrogates impediments. This symmetry will enable its proponents to challenge the orthodoxy of liberalism as well as feminist bioethics, asking and answering a wider range of pertinent questions about the self, social identity,
autonomy, and medicine than what can be given from conceptual systems indebted to liberalism humanism.

NOTES ON TERMINOLOGY

I will digress very briefly here in order to clarify a number of terms and concepts that are central to the critique I intend to level against both liberal and relational accounts of autonomy. The first concept is that which is referred to within the Continental tradition as a “subject.” Liberal philosophy typically refers to individual selves as “persons” or “individuals,” and is interested in characteristics of “the self” that may be universalized. The Continental tradition, following from Hegel, refers to individual beings as a “subject.” Hegel’s master-slave story explicates the Enlightenment conception of individual selves as universal, autonomous “subjects” (Fraser 2000; Weir 1996, 21). It is the autonomous subject that is the liberal tradition rests upon and refers to by way of “the self.”

On the Hegelian model, one becomes a subject by virtue of recognizing, and being recognized by, another subject; recognition is necessary for an individual being to have a sense of themselves as an “I” (Fraser 2000). Within western metaphysics, binary or dualistic structures govern the intelligibility of the subject (i.e., self); a negation of the Other from the Subject is therefore entailed within this social symbolic order. Allison Weir describes that for relational, poststructuralist, and postmodernist theorists alike there is a common assumption that the identity of a self (i.e., self-identity, one’s understanding of oneself as an “I”), necessitates an exclusion and opposition to the other and a negation of non-identity. The universal subject is “separated from and opposed to its object/Other” (Weir 1996, 190). The object/other is a negation of the masculine subject and is marked as undetermined; it does not offer a substantial identity from which claims on others can be made (Butler 1990, 140). Thus the ability to partake in the social symbolic order as a speaker and rights-bearer (a subject) at all is conditional on identification with the masculine and repression of difference (Weir 1996, 168-171).
Thinking about the subject | object relationship brings me to a second term, “monological,” which is employed as a descriptor for a particular form of reasoning or logical structuring of a social order that has been dominant in western epistemology at least since Descartes. A “monological” worldview is one in which the dominant system of reasoning is based upon a singular subject who observes and interrogates a plethora of medium-sized objects in the world. A binary subject’s stance is detached from its object(s) and is thereby able to offer propositional knowledge of objects in the world. Within liberal philosophy, “subjects” are detached, universal, objective, and distinct from possible objects of knowledge; liberalism is thereby connected to monological forms of reasoning. A monological model removes epistemic judgments from the context in which they are produced, including the social positions of knowing subjects and, importantly, relationships between differently situated knowers. By widely instituting a social imaginary of monological reasoning as the way that knowledge is produced, this monological model might be thought of as a “worldview.”

Given that liberalism (in light of its monological worldview) embraces universal standards and generic subject positions, the negation of “difference” through the subject-object relationship is said to be a form of denial or repression. “Difference,” as I am employ the term, is shorthand for the excluded or negated terms that are given in binaries such as man | woman, mind | body, and self | other, which cannot be brought into culturally intelligible terms. As liberal views rely on a unified subject/self, endowed with universal capacities for impartial reason and critical reflection, the incomprehensible, contradictory, or paradoxical aspects of the self are expunged (Scheman 1997). Within liberal philosophy, a person who is capable of participating in society is one who is recognized as a co-citizen by other co-citizens. But these co-citizens are not particular individual selves—they each have a claim to a universal social identity (i.e., they are each singular, unified “subjects”). The comprehensibility of a universal social identity is based on ideals such as universal capacity for reason, equality, as well as
notions of rights, obligations, and responsibility (Weir 1996, 2). These ideals are connected, as I have detailed previously, to liberal notions of autonomy. Here, then, is the theoretical foundation for claims that the values associated with liberal autonomy unilaterally ascribe exclusionary categories of “difference” to those who do not live up to its ideals.

A singular, unified “subject” understood through a monological worldview can be contrasted with a view of “subject” that stems from relational/dialogical models of reasoning. In a dialogical mode, knowers (subjects) are differently situated (not transcendent) and particular (rather than objective). Knowledge does not simply amount to a collection of propositions in the form “S knows that p.” Self-identity based on dialogical models emphasizes the way in which a self/subject is interconnected and heterogeneous; accordingly, this view of “the subject” attempts to embrace, rather than negate, difference. A notion of “intersubjectivity” is also salient to this discussion. While a monological model links to objectivist understandings of the world, dialogical models are connected to intersubjective ontologies. Intersubjective (“between subjects”) refers to the ways in which norms and beliefs are shared meanings that are embedded within institutions and practices at a societal level and mutually constructed amongst subjects, through agreement as well as refusals or resistance. Intersubjective meanings are part of the background conditions (including historical relationships within systems of thought) within which actions take place and are given descriptions in ordinary language. Contra Cartesian philosophy, intersubjectivity refutes the notion of an isolated mind and is thought to bridge the self | other dualism.

THE RELATIONAL SELF AND FEMINIST BIOETHICS

Returning to my assertion that a more radical critique of liberal autonomy may also apply to relational accounts, I want to examine three accounts of autonomy that are employed within bioethics and are arguably constitutively relational. Each of these accounts falters on the grounds I articulated earlier: they do not extend their analyses to give a thoroughgoing
interrogation of what it means to support, achieve, or engender autonomy. The accounts I examine, given by Ann Donchin, Susan Sherwin, and Susan Dodds, pay careful attention to the effects of institutions and social structures for patient autonomy. They fail, however, to explicitly address what I will refer to as the “critique of the subject.” This critique, which I describe in greater detail in the following section, is given by a diverse set of detractors of individual autonomy. It argues against liberal-informed conceptions of autonomy on the grounds that self-identity and the capacity to act depend on the uptake of disciplinary and subordinating norms and practices (Mackenzie and Stoljar 2000, 10-11). That said, I do believe the accounts given by Donchin, Sherwin, and Dodds have the necessary theoretical foundation to contend with the worries raised by a critique of the subject. But before I suggest how this might be the case, it is necessary to discuss the limitations of their respective accounts, in order to get a critique of the subject up and running.

Ann Donchin argues that a reformulation of autonomy is both warranted and possible, so long as it has a central place for positive conception of human agency that recognizes relational experiences as an integral dimension of individuality. Individual subjects are configured by complex and specific social relations (Donchin 2001, 367; my emphasis). Elsewhere, Donchin argues that theories of autonomy should not only recognize the significance of social relationships as the ground for autonomy-related capacities, and that an account ought to make the stronger claim that there is a social component built into the very meaning of autonomy (Donchin 2000, 239). Autonomy is relational in this sense because it is not an individual enterprise and involves a dynamic balance between interdependent people and overlapping projects (ibid). It must also take into account how a person’s capacity to be self-determining depends on a network of relationships (240). Donchin’s “strong relational autonomy” envisions autonomy from within structures of power and authority (ibid, original emphasis). This last point is Donchin’s most promising insight into what it means to have a relational account of autonomy.
But in her discussion of genetic-related decision making in health care, Donchin emphasizes that the above observation should be employed in an effort to “take full account of relevant ways in which individuals and their families are differently situated in relation to one another and to health-care resources” if service providers are going to facilitate the active participation of all family members (including those who are less powerful) in decision-making processes (253). Later work by Donchin embeds this focus on social barriers to autonomy to a greater degree—emphasizing that the value of feminist relational reformulations of autonomy is in their ability to pick out the ways in which social contexts (including medical encounters) can diminish the agency of women (Donchin 2001). While both of Donchin’s contributions to feminist bioethics outline laudable goals for a relational account of autonomy to achieve, they, like the examples that follow, have an overwhelming focus on identifying problematic circumstances for autonomy and then demonstrating how health care providers might facilitate a resolution to such problems using a relational approach.

In Susan Sherwin’s discussion of a relational approach to autonomy in health care, she writes that autonomy is an attractive ideal for feminists because of the way that widespread sexism and other deeply entrenched forms of oppressive patterns are manifest in health care system, e.g., through determinations of credibility and competence, which inform whether one is capable of consent. Autonomy is contrasted with heteronomy, and given an important place for those who have good reasons to oppose medical domination that manifests as paternalism (Sherwin 1998, 23). Sherwin also argues, along with Carolyn Mcleod, that certain self-regarding attitudes (particularly self-trust) are necessary for the ability to act autonomously. Oppressive social conditions undermine self-trust through the internalization of a sense of social worthlessness and incompetence (Sherwin and Mcleod 2000, 262). Thinking about autonomy relationally, the authors write that within the health care system, care needs to be taken to enable patients in disadvantaged and vulnerable social positions to feel validated in their legitimate
claims for care and avoid personal blame for conditions in which oppression seems to be a contributing fact (270-271).

For her part, Susan Dodds argues that relational approaches do not narrowly focus on *choices*, but on the ways that medicine and health care practices can contribute to enhancing or impeding the capacity for autonomy. Dodds argues that those who receive long-term or residential care may be significantly socialized through the health care system. She is concerned that “some health-care settings can significantly inhibit the development of the skills that constitute autonomy competency, quite independently of the exercise of those skills in medical decision making” (Dodds 2000, 229-230). She postulates that services in such settings might be better organized to foster, rather than frustrate, the skills that are needed for autonomous decision making. Dodds also looks to how a relational account can clarify the impact of personal medical emergencies, trauma, and terminal diagnoses on autonomous agency, vis-à-vis their impact on self-conception (Dodds 2000, 230-231). Dodd’s relational account therefore moves away from the tendency of mainstream accounts to operationalize autonomy as informed consent and “choice” in medical decision-making, and toward a view of how health emergencies, medical conditions, and medical systems negatively alter self-conception and autonomy-related skills, and how the same system might provide redress for these challenges to autonomy.

As with other relational accounts of autonomy, the theoretical emphasis of these views is overwhelmingly on how power relations can *undermine* autonomy. I concur with the authors’ contentions that they are offering a different view of the self, and that this has implications for what “relational” means when giving an account of autonomy. The emphasis on the capacity for self-trust and the ways of understanding issues of consent as being dependent on one’s position within a given institution both speak to a more dialogical model of the self and implicitly argue against the notion of a core, authentic self. Similarly, situating autonomy *within* structures is certainly important.
But as I will attempt to demonstrate, the accounts do not address the challenges raised by a critique of the subject. I will detail this critique shortly; for now, consider Judith Butler’s observation that the acquisition of autonomy skills\(^{16}\) is embedded in the very power relations that are adjudicated using those same skills (Butler 1995). Taking Butler’s point seriously entails that Dodds would need to more critically question what it means for health care providers and long-term and residential care institutions to “foster” autonomy, and whether this fostering doesn’t also implicate relationships of authority and control. Dodds’ view is helpful for its explication of how autonomous agency is impacted both positively and negatively by health care institutions, policies, and professionals. It just needs to go farther, treating the enhancement of autonomy within health care institutions to the same level of criticism she applies to the more obvious problems of impediments to autonomous agency. Dodds’ account needs to explicitly recognize that achieving or enhancing autonomous agency (even relational) is not beyond question. Her interest in illness and self-conception ought also to extend to an analysis of the ways in which novel forms of obligation, responsibility, and social action are produced by medical practices through the influence on self-conception (Rose 2001; Fraser and Valentine 2008).

Likewise, Sherwin’s account would need to more carefully lay out the challenges that accompany increased emphasis on personal control, choice, and responsibility for health, as Foucauldian scholars do in their considerations of technologies of the self. In discussing narrow approaches to autonomy within informed consent procedures, Sherwin cites Foucault’s work on discipline and docile bodies, but she fails to engage with Foucauldian insights on the liberatory aims of medicine. These liberatory aims are argued to require subjects’ uptake of risk categorizations as part of the constitution of their social identities as well as demand self-regulation and self-discipline in order to embody “health.”\(^{17}\)
While I agree with their general approaches to relational autonomy, my purpose in emphasizing these challenges is to indicate the ways in which even constitutively relational reconfigurations of autonomy can falter. This discussion has particular salience for feminist bioethics. Dodds’ own position was motivated by her concern that the narrow focus of mainstream accounts of autonomy, on “choice” and informed consent, leaves out of the picture a number of pressing issues that are within the scope of autonomy theory, such as institutional factors that impede or enhance the exercise of autonomy. I want to suggest that a constitutively relational account of autonomy that fails to extend its *critical* gaze to the achievements of autonomous agency, and fails to appreciate the challenges in positioning or motivating critique in light of the ubiquity of power relations, will likewise leave important issues off the table. As I detail further on, my empirical research in the field of HIV/AIDS programming and policy indicates why this is of concern to feminist bioethics. Feminist reformulations of autonomy cannot only be about how to ensure that more people are autonomous. If they are to be distinguished from problematic liberal accounts of autonomy, relational reformulations must recognize that autonomous agency is *always* bound up with power. Until this is the case, feminist analyses of autonomy within bioethics will remain affiliated with the liberal orthodoxy and its analyses unnecessarily constrained.

**A CRITIQUE OF THE SUBJECT**

I hope it will become clear over the remainder of this chapter that even relational accounts are not immune to the challenges raised by a feminist critique of the subject. I take this to indicate that an adequate relational reformulation of autonomy will not *jettison* this critique, so much as it will attempt to understand what it means for an account of autonomy to work within it, and offer details as to what such as conception of autonomy might entail. The complex and varied body of work that I am referring to as a “critique of the subject” suggests that participation in liberal societies and the ability to be seen and heard (i.e., recognized as a speaker
with legitimate claims on others) requires that one be recognized as a subject on culturally intelligible terms set by a dominant culture. Misrecognition, e.g., by way of demeaning and distorted images of a particular social group, alters a group member’s sense of themselves as well as their ability to make public assertions and claims on others, particularly those who are representative of dominant social groups. The critique of the subject emphasizes the ways in which mutual recognition and respect are in fact contingent on norms set by dominant cultures, which may be experienced by certain groups as subordinating. Recognition is not granted willy-nilly—it is granted on the basis of capacities that are universalized from a particular perspective. For instance, in contemporary western societies, one’s ability to reason must conform to standards set by the dominant culture; it must be culturally intelligible on the terms that liberalism provides, in order for one’s reasoning be acknowledged as a representative instance of a universal capacity. Reason, for liberalism, is argued to be instrumental, objective, disembodied, and unsituated. Those who do not reason in this fashion are not imagined to share in this capacity and their status as subjects called into question.

Scholars who take up various elements of a critique of the subject attempt to deconstruct the regulatory norms of western liberal thought as they relate to self-identity. Patricia Clough describes Judith Butler’s argument in *Gender Trouble* in this way: Butler claims that being able to participate as a full citizen, i.e., to be culturally intelligible, requires that identity is singular and that “full citizens” disavow or repress any and all aspects of themselves that reveal a disunity with normative standards. This enables the normative standards be reproduced. Butler focuses on norms of sexual difference (i.e., a clearly delineated male|female binary), which exist within a heterosexual matrix that regulates the production of certain bodies and certain practices of desire; norm given by a liberal framework, e.g., of rational action, operate in a similar fashion. Only some bodies (and some actions) are intelligible within modern western social practices and systems of thought (Butler 1990; Clough 2000). Clough writes that, “the cultural intelligibility
of bodies depends on the exclusion of other bodies, making them unthinkable, abject, even unliveable” (Clough 2000, 334).

My own worries about circuitous pathways in health and the depiction of certain identities as being “chaotic” and pathological come to bear on the way in which liberal autonomous agency functions as a regulative norm, similar to how Butler describes norms of sexual difference within a matrix of heterosexuality. Culturally intelligible bodies are the ones that can sit within the internal boundaries set by liberal autonomous agency. By failing to comply with these regulative norms, women who are drug using and HIV-infected may be envisioned as abject; my looping effects argument indicates that the normative framework makes their ascribed identities unliveable in a profoundly material kind of way. As I argued in Chapters Five and Six, these pathologies are, in many ways, contingent on ideals of a dominant culture.

In a related vein, liberal views are said to sweep away difference, conflict, and division, within individual as well as collective identity. Here is another challenge made on the basis of a critique of the subject. Detractors of liberal autonomy largely criticize notions of unified identities and uniform experiences, be they traditional liberal notions of the self, or group identity that presupposes unity within the collective. This aspect of the various critiques of the subject is given predominantly on the grounds that notions of universalism, ideals of unification, and projections of coherency have a tendency to essentialize experience and identity, while excluding difference. The coherent self that liberal philosophy holds as autonomous simultaneously denies its own heterogeneity.

Similarly, relational accounts of autonomy that attempt to give kinder, more gentle readings of universal values will not adequately engage with the terms of this critique (Shildrick 2008). In a discussion of Donchin’s review of feminist bioethics in the Stanford Encyclopedia of Philosophy, Shildrick argues that feminist bioethics has yet to substantively engage with the disruptive critiques of autonomy such as are given by critiques of the subject. For as much as
abstract universal norms are denigrated by relational accounts like those of Donchin and Sherwin, universal principles seem to creep back into feminist bioethics repertoire. They look different—articulated as non-exclusionary and relational—but little has unsettled the overall tenor of the liberal humanist canon (Shildrick 2008, 31-32).

It is in light of the challenges raised by a critique of the subject that Iris Young argues identity and difference to be mutually exclusive (Young 1990). The issue here, which both liberal and relational accounts of autonomy are faced with, is the way in which self-identity is predicated on symbolic language. The very possibility of being recognized as an author of one’s own actions and a participant in a social order compels conformity to socio-linguistic structures that subordinate positions construed as “negations” within oppositional binaries. Because participation requires identity (i.e., that one be able to take up a recognized subject-position), subordination is argued to be a condition of possibility for the self/subject (Allen 2008, 75). In The Psychic Life of Power, Judith Butler conveys this point in her discussion of Althusser’s account of interpellation. She argues that the emergence (physically and developmentally) of an individual into a position of subjecthood necessitates relationships of dependency and, ultimately, subordination. The promise of identity and recognition of one’s social existence compels one to “turn toward” the dominant social symbolic order (represented by the singular speaking officer of the law) in order to become culturally intelligible (Butler 1997, 106-108). By emphasizing the way in which heterosexism is the matrix within which the social symbolic order is formed, Butler demonstrates how participation in it requires one to identify with mastery and the patriarchal law.

Although there is the potential for subversion of the law (escaping self-identity), the subject is vulnerable to subordination within this dependency relationship because the desire for recognition can lead to the acceptance of, and desire for, oppressive and subordinating forms of attachment (Butler 1997, 7-8). In contrast with the emphasis placed by mainstream ethical and
political philosophy on *enabling* the ideals of integration, coherence, and rationality, Butler’s analysis draws us into contending with the *necessity* of conditions of subordination for the emergence of the subject.\(^{21}\)

This challenge, which operates at the level of individuals, can be raised to the functions of liberal autonomy at a group level as well. Liberalism encourages the creation of social/political structures that protect shared interests and that foster a variety of conceptions of the good; if successful, co-citizens can endorsed these political structures regardless of the diversity of their individual best interests (Christman 2004, 153). Within this structure, resolutions to dilemmas of policy and law use terms set by procedures impartial reason so as to maintain citizens’ endorsement. And although difference can be part of the discussion when it is uncontroversial that special consideration is warranted, determinations of special consideration must happen according to the normative standards of liberalism—the very standards that claims from “difference” attempt to undermine as problematic. Thus, the conceptual infrastructure of impartial reason is argued to be homogenizing and insensitive to the exclusionary tendencies of liberalism as well as historically despised forms of difference (Meyers 1994, 23-24).

We can see the force of this challenge when Sunstein tries to give a liberal account of how “deforming” norms might be transformed through better information and reflective judgments. Here, he fails to recognize the ways in which deep-seated prejudices are often impervious to reason—when the problems of norms and prejudices are understood in psychoanalytic terms, it is more plain to see that norms become fossilized as cultural figurations that need not be reflectively endorsed in order to be transmitted (Meyers 1994, 55). Such figurations unconsciously enter the political realm through policy and lawmaking. Captivating systems of imagery—myths, cautionary tales, figures of speech—are memorable and emotionally compelling; they resist critique through the linkages they offer between disparate conceptual and experiential domains (52-53). The depiction of straightforward political self-
identity for those shaped by unproblematic ("good") norms and roles, and tendency toward
exclusion of those who fail on liberalism’s own terms, ultimately means that a self-other binary
remains in place.

My discussion of negative agency in the previous chapter indicates why an account of
autonomy is pressed to contend with this issue. The biomedical model of health care takes a
certain standard view of what the rational autonomous patient is like; this view is designed
around a normative liberal framework. When the system is confronted with individuals who do
not live up to the normative framework, problems arise: the standard view of patients organizes
the set of treatments offered, and those who are unable to partake because of the normative
framework can only be understood in the terms that the framework provides. In the cases I have
been describing, patients are envisioned by health care providers and the general public as
irrational or irresponsible. As my methodological discussion indicates, the problems of non-
engagement in care and non-adherence to therapy are also investigated according to the same
normative framework, such that the possible factors related to the problems and their solutions
are given according to the terms and standards of the biomedical (i.e. liberal) model. For
differences that cannot be subsumed under the guise of the normative liberal standards,
pernicious tropes and figurations abound; backed by a supposedly neutral view of rational
autonomous agents, the effects (difference, pathology) are construed as a given, burying the
power relations and political economies by which they were constituted.\textsuperscript{22}

This last issue also speaks to the challenges faced by constitutively relational
reformulations of autonomy, which I have argued do not extend their analyses far enough. Now
it is not the case that these views operate according to a monological worldview. They tend to
employ an intersubjective account of human social life and human selves as the foundation for
autonomy. But an intersubjective understanding of social orders (and the selves within them) is
not grounds to suppose that the validity of the substantive content of such a relational account is
somehow transcendent of its particular context. Even non-exclusionary normative structures cannot claim to be universal. My discussion of the need for relational accounts of autonomy to interrogate achievements of autonomy as much as the barriers to it is in the spirit of Amy Allen’s argument against context transcendence. Allen argues that we must “be more historically self-conscious and modest about the status of our normative principles…” (Allen 2008, 180). Even a constitutively relational account will run into trouble if it does not adequately address normative ideals in light of a contextualist approach to autonomy itself.

RECONFIGURING AUTONOMY RELATIONALLY

For as much as the critique of the subject sets up a number of decisive challenges to liberal accounts of autonomy as well as relational reformulations, this critique is rather troublesome for feminists in another way. The citation from Jacqueline Rose at the outset of the chapter emphasizes the nature of the problem: one has no politics—no standing from which to make claims on others—without the ability to assert a non-pejorative, culturally intelligible identity. Although it will not suffice to premise autonomy on a transcendental self that operates outside of systems of privilege and power, it is equally untenable to suggest that the alternatives are to submit to subordination and a repressive logic of identity, or have no social existence at all (Allen 2008, 83; Weir 1996, 184). If one has no possibility of a positive and alternative constitution of identity, then it seems there is no way to negotiate or contest cultural authority (Fraser 1990, 85). And of course, this is one of the central concerns for feminist reformulations of autonomy. Put differently, the trouble with arguing that socialization is the basis for self-identity and at the same time is the mechanism that maintains social structures of domination is that it is awfully difficult to theorize a critical vantage point for resistance to modes of oppression and women’s claims to agency and responsible self-determination (Allen 2008; Wendell 1990, 17-19).
An adequate reformulation of autonomy must therefore be able to address the challenges posed to liberal autonomy (and some relational accounts) by postmodernist and poststructuralist theories—issues concerning identity and the constitution of the subject—without neglecting the necessity of having a position from which to make claims. As critiques of the subject emphasize, a major implication of the relational self is that the capacity for reflection is possible only through the very structures of power/discourse that critical reflective processes are directed toward. But in order for a relational account of autonomy to move away from the problems posed by this issue, problems I have harangued liberal accounts of autonomy with, a relational reformulation has to provide a framework that can offer an understanding of identity that need not repress difference. A reformulated account must also articulate how intrinsically social accounts of autonomy can function without presupposing that autonomy is itself free from values, interests, and relationships of power. This means conceptualizing how both achievements of autonomy and barriers to it are only possible within and through relationships of power.  

With respect to the issue of difference and identity, I turn to Allison Weir’s work on the critique of the subject. Weir argues that a false assumption underlies the claim that identity necessarily represses difference. The assumption, that identity is totalizing and can only admit of its opposition (spontaneous self-creation), seems true if we take a monological model of reasoning as given. Because Weir herself employs a dialogical model, and understands meanings, norms, and ideals to be constructed intersubjectively, difference need not be negated (there are multiple possible subject-positions) and identities can be founded on connections with others (Weir 1996, 186). She does recognize that self-identity requires some capacity to reconcile multiple and conflicting identities, but this need not be a metaphysically deep understanding of coherence. Within a dialogical model, self-identity can be defined as the
capacity for a person to be an active and relatively coherent participant in the social world, one who relates to others and to him or herself in a meaningful way.  

The relational features of the self that Weir describes as being central to a dialogical worldview—embeddedness in context, connection, and heterogeneity—do sometimes lead to the fragmentation of identity, particularly amongst those for whom membership in social groups invoke conflicting norms, roles, and images. Unlike liberal accounts, which project a pathological view of the self that embodies these qualities (e.g., describing it as fragmented), Weir’s account does not negate autonomous agency on the basis of these relational features of the self. Two issues are of note, with respect to this particular aspect of Weir’s view: first, the degree to which fragmentation might be called “problematic” is arguably related to the extent to which dominant norms and roles demand conformity to the terms they give. For any given social order, the greater the reliance of dominant normative frameworks on unification, stability, and universalism with respect to the self, the less such frameworks are able to embrace difference and multiplicity. Maria Lugones argues this point, describing fragmentation as a form of domination that is predicated on the reduction of multiplicity to unity (Lugones 1994, 463-464). Accounts of autonomy that are predicated on dialogical models of engagement with knowledge, subjectivity, politics, ethics, agency, etc., posit multiple subject-positions and therefore offer avenues of self-identity that need not repress difference or reduce complexity. On a dialogical worldview, it may be possible to live with and attempt to make sense of difference and connections with others.

Second, even when it is the case that heterogeneous and non-unified identities are understood as representative of a fragmented self (in relation to norms of stable, coherent identity) there is still a way that experiencing oneself as fragmented and heterogeneous may open up possibilities for a critique of cultural institutions (e.g., those of contemporary liberalism) that regulate familiar identity categories (Lugones 1994; Weir 1996, 187). As Weir rightly points
out, dissociation from normative frameworks and systems of knowledge can be possible even within oppressive social system, through a sense of alienation from this dominant structure.\textsuperscript{28} When actions understandable in one context fail to generate meanings in another context (or generate very different meanings), individuals carrying out the actions experience themselves differently, as though they exist within (and between) two (incommensurable) realities.

When an individual lives on the border between the two worlds, they become more keenly aware of the multiple senses a person might have of him or herself, and of the contingency of the institutions governing the disparate worlds (Anzaldúa 1987; Lugones 1990 503-505). It is not necessarily the case that oppressive socialization precludes the capacity for critical reflection, although Weir certainly recognizes that the challenges for reflection increase in difficulty when contending with systems of oppression.\textsuperscript{29} Although oppressed individuals may come to closely identify with and endorse the normative structures that maintain their marginal positions,\textsuperscript{30} Weir’s relational view of the self also has the theoretical resources to contend with the feminist worry that recognizing the influence of oppressive conditions on self-conception undermines the capacity for those in subordinated social positions to understand and criticize the social structures that they are compelled to identify with.

This is not to say that relations with others are without their own set of problems and challenges. Butler’s argument, that recognition and social/political standing require an adoption of the patriarchal laws of the social symbolic order, manifest these challenges. Amy Allen describes Butler’s analysis as ambivalent toward the possibility of non-destructive forms of recognition and interrelatedness: given that one’s recognition as a subject is bound up with power, Butler’s account presumes that intersubjectivity (the basis of this recognition) is bound up with power as well (Allen 2008, 89-91). Claiming that intersubjectivity provides the capacities for critical reflection and self-determination (i.e. the conditions for autonomous agency) entails that the constitution of the subject and achievements of autonomy are so as well.
To this issue, Allen argues that although dependency on a given social symbolic order (as conditions of community and communication) may be dangerous because of the vulnerability to subordination, subordination need not necessarily follow from this vulnerability. Being able to engage intersubjectively in the world depends on the capacity to participate in communities—but not all communities and not all groups offer participation at the cost of expunging difference, heterogeneity, and particularity (Isaacs 2002). Even if new cultural meanings and refutations of dominant norms can only be generated intersubjectively, not all intersubjective relationships preclude mutual recognition and respect, even for those whose identities are maligned within a wider community. That said, the intersubjectively developed capacity for critique has its limits—this demands greater self-consciousness about normative principles as well as the understanding that their validity cannot be context transcendent (Allen 2008, 179-180). But to my mind, this suits the way in which our knowledge of ourselves and of different others has to have its limits if it is to refrain from being a dominating mode of engagement.

Weir’s relational account of the self indicates that autonomous agency requires a certain self-understanding that is defined and sustained in dialogue with others. In a parallel fashion, we might think that a relational account of autonomy per se means that autonomy itself is constructed through discourse. This indeed moves us farther from the traditional notions of autonomous agency, but toward the issues that I have argued must be contended with. In her discussion of autonomy and subjection, Allen argues that, despite how often he is read, Foucault does not articulate either the death of the subject or a rejection of autonomy; rather, a capacity for deliberative self-transformation is implicit in his notion of technologies of the self (Allen 2008, 173). Technologies of the self enable individuals to transform themselves by their own means or with the help of others in order to attain a desirable state (Foucault 1988, 18). The technologies by which one engages in care of the self are historically contingent—the practices of confession, for example, have a different function in early Christianity as compared to
modernity. Within modernity, techniques of verbalization are informed by the human sciences so as to constitute a new self, through oneself (49). Taking a cue from Foucault’s discussion of technologies of the self, we might think that understanding autonomous agency as constitutively social per se is to see it as an intersubjectively developed capacity; its standards and ideals (relational or otherwise) rooted in the context of late western modernity (180). The “nature” of autonomy would therefore be contingent on its historical and discursive context.

In what I take to be a compatible line of thought, Lorraine Code uses the term “autonomy” to refer to a locally specific value that is conflated with self-sufficient individualism in its more hegemonic articulations, but that might be reconfigured along the lines of mutual and interlaced recognitions and responsibilities that are relational all the way down (Code 2000, 196-198). The instituted imaginary of late western modernity holds in place the monological worldview that I have argued, following Code, interlocks with the assumptions of liberal autonomy. A relationally reconfigured model of autonomy may provide a different set of conceptual resources with which to understand the world and conceive of alternate social meanings, values, and expectations. To understand autonomy as relational per se is to appreciate how this reconfiguration is just as much a product of a social imaginary as that of the individualist and hyper-rationalist accounts. On this sketch of what it would mean for autonomy to be relational per se, it seems that the normative commitments of a relational account may not be beyond reproach, depending on the particular vantage point one examines them from. But it also calls upon its adherents to be more self-conscious about the values they espouse, and more attuned to the potential for those values to wield the effects of privilege and social positioning.

LIBERAL PHILOSOPHY AND THE RELATIONAL SELF

Constitutively relational accounts of autonomy that are predicated on a relational view of the self are perhaps the most widely agreed upon versions amongst relational theorists. I have suggested that these accounts are not free from a critique of the subject, but I have also tried to
point to ways in which constitutively relational accounts may offer the resources to contend with these challenges. This begs the question whether a causally social account of autonomy, given from a liberal position, might likewise do the same. For example, in defense of what he deems to be a socially nuanced liberal conception of autonomy, John Christman argues that there is “nothing about a social conception of the “self” that is incompatible with an individual conception of autonomy” (Christman 2004, 146). I have a number of misgivings about the basis of Christman’s argument, but I want to use his statement to answer a question that is implied by his position: why is it that liberal conceptions of autonomous agency are unable to help themselves to these theoretical resources for their own accounts, accepting that the self is relational but arguing that autonomy is not?

Methodological individualism and an acceptance of monological model of reasoning within liberal thought preclude any robust or sophisticated understanding of the sorts of concepts (dialogical reasoning; intersubjectivity) that allowed constitutively relational accounts to respond to a critique of the subject. Even amongst liberal accounts of autonomy that posit social conditions as important causal factors in the capacity for autonomous agency, liberal accounts abstract away from the particularities of persons (i.e., “subjects”) in order to craft a concept of a universal subject that can then be attached to political roles, as those roles are defined by liberals. The “subject” is thereby understood on liberal views as a uniform, unsituated, generic category; egalitarianism, which is very often predicated on impartiality, is likewise connected to the generic subject-position given by liberalism (Code 2006, 170; Meyers 1994, 4-5). But as my critique of Sunstein’s analysis emphasized, figurations and images of ideal agents that conform to and confirm the supposedly universal standards for objectivity, equality, and civic participation are by no means value neutral. They are modalities that socially position certain members of society and prioritize certain ways of knowing and engaging with the world. They are embedded within what Hélène Cixous describes as phallocentric and colonizing patterns of
speech (Cixous and Miller 1993, 18). The Foucault/Butler insights regarding subjection compel the conclusion that no particular understanding of autonomy, rationality, or practical reason can be defended as insulated from power on the basis of presumed universality, context transcendence, or value-neutrality (Allen 2008, 8-9; 120-122). This will be the case, whether the norms are endorsed as reflective of universal impartial reason, or on the basis of intersubjective agreement.

Lorraine Code’s work on autonomy and epistemic dependency offers an additional way in which we might scrutinize liberal accounts in light of a critique of the subject. Because a monological worldview disqualifies overtly situated knowers (i.e., knowers who are obviously reliant on others) from bring recognized as knowers, this model reinforces dependency amongst those who are constructed as failing to embody normative standards of the liberal subject. Such individuals are unable to readily make claims based on their experiences and understandings without the guidance of others in positions of privilege (Code 2006, 170-172). Certain would-be knowers (non-male, non-affluent, non-white) commonly have their experiences discounted, their testimony refused, and their participation blocked (170). This dependency is apparent in the health care field, as I discussed in Chapters Four and Five; the discounting of experience is often carried out on the basis of dominant images of those who bear the status of maligned social identities as irrational and lacking credibility.

Liberal accounts of autonomy will not be able to avoid dichotomizing autonomy and dependency. Similarly, autonomy understood on a liberal view of self-determination and epistemic self-reliance is contradictory to the understanding that the subject is constituted within and through interlocking systems of authority, privilege, and techniques of domination, and that these interlocking systems structure who is able to make claims to objectivity, the truth of their own experience, and ultimately, knowledge. Attempting to sprinkle some social context or a bit
of interpersonal relationships onto this account cannot adequately contend with the challenges raised by the Foucault/Butler critique of the subject.

In order to endorse the view that critical reflection and transformation of normative codes may indeed be premised on a relational view of the self, an account of autonomous agency must be able to theorize how autonomy is constituted within relationships of power, and not simply opposed to these (Allen 2008). Although I employed their respective views as a way to get a critique of the subject off the ground, Donchin’s, Sherwin’s (including the contributions of Mcleod) and Dodds’ accounts of relational autonomy are commendable, insofar as they begin to provide the conceptual grounds for addressing the sorts of concerns I leveled at liberal accounts of autonomy. Sherwin refers to her relational approach as “socially situated” (Sherwin 1998, 19) in the sense that, “autonomy is both defined and pursued in a social context and that social context significantly influences the opportunities an agent has to develop or express autonomy skills” (Sherwin and Mcleod 2000, 259-260; my emphasis). Likewise, Donchin and Dodds both make this aspect of their definitions of relational autonomy clear. Moreover, Sherwin describes herself as being “ambivalent” about autonomy, particularly because autonomy language is often used to hide the workings of privilege (Sherwin 1998, 25). I read these definitions as endorsing a conceptual framework that enables the recognition that any account of autonomy will be a construct of modern western societies; the improved upon criteria of relational accounts are no less normative than those of mainstream liberal accounts. The discussion might, therefore, get us somewhat closer to the concerns raised by the critique of the subject, and feminist responses to it.

WHAT CAN RELATIONAL AUTONOMY ACHIEVE?

I can hear you say, “What a horrible, irresponsible bastard!” And you’re right. I leap to agree with you. I am one of the most irresponsible beings that ever lived. Irresponsibility is part of my invisibility; any way you face it, it is a denial. But to whom can I be responsible, and why should I be, when you refuse to see me? And wait until I reveal how truly irresponsible I am. Responsibility rests on recognition, and recognition is a form of agreement.

(Ralph Ellison, The Invisible Man)
At the outset of this chapter, I argued that supporters of liberal accounts of autonomy tend to base their endorsement on practical concerns rather than metaphysical ones. The pragmatic motivations of a liberal account are, I think, widely based on Mill’s insight that autonomous individuals are generally in the best position to decide their own good for themselves, and that doing so enhances the diversity of available conceptual resources for society to draw on and prosper with. Accordingly, liberals worry about whether postmodernist critics are not missing the mark in their complaints about liberal autonomy. That said, my own sketch of relational autonomy is able address the issues that mainstream liberal views employ to assert their superiority. To recount, those issues are: (1) articulating the capacity for an agent’s reflection on their own best interests and the role of reflection in self-determination; (2) motivating mutual recognition and respect for persons (3) determining responsibility for actions in light of normative standards and social structures (4) understanding the self as an epistemically autonomous knower who is capable of both objectivity and reflective judgments.

The first of these issues has been dealt with extensively through my discussion of the critique of the subject. My analysis has indicated that a relational account of autonomy that is informed by the critique of the subject seems to be better positioned to explain the capacity for reflection and the role of self-determination, especially under non-ideal (i.e. true to life) conditions. The critique of the subject does bring about challenges for mutual recognition, insofar as identity is predicated on forms of recognition that make one vulnerable to subordination. But as I have indicated above, mutual and non-dominating recognition is possible, when it is given within a dialogical model. This model understands that subjects have a relational identity, but it does not homogenize or assimilate these in terms of a single subject position. Recognition is a problem, however, when it is based on a universal capacity for reason. Because it embraces universal standards and generic subject positions, recognition is a concern
for liberal accounts of autonomy, given its connection to the repression of difference. As I have argued in earlier chapters, the normative standards of reason are quite often given from a particularly privileged social position, and serve to undermine and exclude individuals on the basis of social identities, rather than recognize them.

Determinations of responsibility have something of a “handshake” agreement with mainstream theories of autonomous agency. On the liberal view, normal adult human beings are presumed to have the capacity to recognize the authority of normative standards, independent of the particular social order in which they live, transcending in thought the limitations of these established standards (MacIntyre 1999, 314). Liberal theorists of autonomy typically charge postmodernist and poststructuralist views with throwing away the plausibility of making determinations of responsibility. How, given the emphasis on the constitution of the self through social systems which position subjects in hierarchical relations of power, can such theories suggest that agents are capable of self-determination or free choice? And the problems mount for those who are subjected to overwhelming domination and oppression within the social system.

This dichotomy between autonomy and responsibility on the one hand, and the relational formation of the self and social structure on the other, is somewhat tiresome. Following Amy Allen, I have tried to indicate how the critique of the unified transcendental self is not a denial of agency, and that agency is instead to be understood as an effect of complex and dynamic relations of power (Hekman 1991; Butler 1993). Given this view of agency, it seems that judgments of responsibility that are relative to their contexts and to the purposes for which they are made are indeed plausible (Wendell 1990, 19). As such, having a view of agents as embedded and particular, and attempting to actually understand the intricacies of the context within which they exist, might make for more apt determinations of responsibility. This view finds favour within feminist philosophy. Margaret Walker, for example, talks of multiple
practices of responsibility.” A model of “practices” presses the question of how social positions, identities and responsibilities operate within a matrix, and how they serve the purposes of some but not others (Walker 1998; see also, Isaacs 2002). Walker’s account of responsibility relies on a relational account of the self and emphasizes contextualism. Her work can be taken as support for my claim that the sort of relational/dialogical model I am putting forward is well suited to address the concerns traditionally raised by liberal philosophy.

Alasdair MacIntyre makes a related point in his answer to the problem of social structure, as posed by mainstream conceptions of agency:

Accountability to particular others, participation in critical practical inquiry and acknowledgment of the individuality both of others and of oneself are all then marks of the social relationships and modes of self-understanding that characterize the moral agent. Strip away those social relationships and that mode of self-understanding and what would be left would be a seriously diminished mode of agency, one unable to transcend the limitations imposed by its own social and cultural order. (MacIntyre, 317)

MacIntyre gives what is in essence a dialogical view of the self, arguing that a different view, e.g. like the liberal account, predicated on a monological view of the self that fails to recognize its particularity and embeddedness, will not be able to offer the capacity to transcend the limits of its structure as it is so keen to do. Responsibility need not be restricted to accounts of autonomous agency that rely on a universal self or transcendental rationality.

In addition, I argued earlier that a monological model of reasoning underpins problems concerning determinations of epistemic responsibility and credibility. Within the health care system, certain individuals, by virtue of their ascribed group membership and the images associated with their group identities, are deemed to fail as epistemic agents; they are therefore denied credibility and the capacity to have their testimony heard and accepted. In contrast, a dialogical model deems these contextual features to be adverted to implicitly in all claims of knowledge. Dialogical model of reasoning are thus able to address the way in which context and
location are part of responsible knowing; the dialogical model is more cautious to deny or affirm
designations of credibility and authority.

Detractors of a monological model of reasoning argue that when it is instituted as
worldview with precepts of objectivity and universal rationality, the model substantiates western
epistemic norms of individualism, objectivity, and self-mastery. These norms are argued to be
homogenizing, phallocentric, and representative of colonial patterns of speech. In contrast, a
dialogical model of reasoning is associated with a view of the self that attends to issues of
responsibility, while emphasizing how the self is situated and neither homogenous nor
interchangeable (Code 2006, 207). The dialogical model motivates a different configuration of
epistemic autonomy altogether. Lorraine Code argues that a dialogical model of reasoning posits
the generation of knowledge claims to be a communal-political endeavor, embedded in
discourses, and informed by interests which can then be scrutinized (Code 2006, 192-193). It
seems that for constitutively relational autonomy that are based upon a dialogical model, a
different account of objectivity and knowledge production is possible; this need not reproduce
structures of domination and the denial of difference. Code suggests that a dialogical model
gestures toward more robust practices of critical reflection and the scrutinizing of normative
standards.

Code’s argument, that epistemic autonomy need not entail a monological model of
reasoning, speaks to one of the purposes of my empirical project through the previous chapters,
which is worth considering for a moment. The empirical discussion I have given is more than an
analysis of whether and how women are adherent to antiretroviral therapy—it has been an
interrogation of liberal humanist norms that operate in conventional medical and research
practices, and their effects upon patients categorized according to excluded or marginalized
group identities. Methodologically, I have been concerned to examine liberal norms when they
appear in concepts such as “rationality,” “responsibility,” and “autonomy,” and not simply
attempt to locate barriers to achieving these normative standards. Here is one set of considerations that we should expect an adequate relational account of autonomy within bioethics to attend to; as an analytic method, this is an example of one way that the relational accounts I have criticized might be improved upon.

**AUTONOMY AND RELATIONALITY IN HIV/AIDS CARE**

The theoretical aspects of my analysis suggest that the priorities of liberal humanism and the liberal account of autonomous agency can no longer be held as privileged or taken for granted. Importantly, the relational reformulation that I have offered does not fall prey to many of the challenges faced by the liberal view, and adequately responds to the pragmatic concerns brought forward by proponents of liberalism. As the final task of this chapter, I give an outline of some of the implications of this constitutively relational account for medicine and research practices, within the field of HIV/AIDS. My critique of liberalism has been founded as much on empirical insights as theoretical ones, and to conclude, I offer a set of empirically driven considerations that respond to the question of what a relational account of autonomy can achieve for feminist bioethics.

**METHADONE MAINTENANCE THERAPY**

So the barriers are the myths about methadone, people think it rots their teeth or their bones, which is not true. They say that it’s harder to get off methadone than it is to get off heroin. Which in some ways may be true, because the withdrawal from methadone will generally go on a lot longer. But the people who are saying that are the people who haven’t been able to stop heroin anyway, so it’s not as if they’re looking at abstinence tomorrow as a real option. Another argument is that people don’t like the hassle of people having to show up at the clinic, go to the pharmacy every day. It really restricts their freedom. Not that they really have that much freedom anyway, when they’re scrambling around every day trying to get the funds to get the heroin. But that’s how they see it. Especially when clinics have hours that people have to wait for people to see the doctor. Those kinds of things are barriers. Some places have mandatory counseling, sometimes that can be a barrier to treatment entry. And then once people enter treatment, some of the things that are barriers to keeping them in treatment are lack of availability of take home doses. The easier it is for them to not have to go to pharmacy every day, seven days a week, the easier it is to keep them in care.

(Physician; addictions specialist)
The interview excerpt offers the view of an addiction specialist concerning some of the barriers to remaining on methadone maintenance therapy (MMT) for individuals in the Downtown Eastside community. Over the course of this project, I have described a number of challenges with respect to substitution therapy with methadone, particularly in its use as a tool for adherence to antiretroviral therapy. While MMT is merely one area that can demonstrate how a relational account of autonomy might function as an explanatory and investigative framework, the excerpt serves as an analytic prompt. The interview can be scrutinized in the following way: what does a relational account of autonomy have to say about MMT, and about its connection to adherence to medical advice, including antiretroviral therapy?

The relational approach includes in its investigative scope the images, tropes, and figurations that become attached to particular individuals as members (real or imagined) of groups. Because the dialogical model entails a symmetrical approach to critiquing the influence of normative structures and ways of knowing the world (where its own presuppositions are as subject to scrutiny as those that it means to undermine), the constitutively social account of autonomy is going to say something about the relationship between ascribed identity and the taken-for-granted challenges faced by those who bear the status of the social identities in question.

The physician above shoots down a number of patient views as to why methadone is challenging—saying that the “addictive” properties of methadone aren’t really an issue because addicts aren’t about to be abstinent anyway, and that their opiate dependence means they are mistaken about both the hassles of the clinic and their own level of freedom or control. Within addictions discourse, the binary between using and being abstinent can function as more than a descriptor of patient behaviour—it marks off achievements of moral character as well as the successful uptake and habituation of techniques of the self (Keane 2000, 326). In some settings,
methadone is described metaphorically as “liquid handcuffs” (Fraser and Valentine 2008, 117), a view that is endorsed by a number of participants in my own work, especially Angel. In an extensive analysis of MMT in Australia, Suzanne Fraser and Kylie Valentine argue that the images of MMT clients/patients as being like children and criminals, and the repertoires and metaphors of treatment (“handcuffs”) work together to reproduce the effects of treatment, which are masked by the value-neutral language of policy (119). By moving out of a monological mode that presumes both value-neutrality and unfettered objectivity, a constitutively relational account of autonomy addresses these concerns, first by recognizing that pernicious social identities exist in relation to certain normative standards, and second, by investigating how these relational identities operate in clinical practice.

A relational account must also attend to the effects of categorizations and ascriptions of identity. MMT programs are concerned with certain categories of people (“drug addicts,” or “opiate dependent individuals”), and have a proclivity for reinforcing designations of its clients/consumers/patients as unreliable, immature, and in need of moral guidance and social structure (Fraser and Valentine 2008, 116). Rather than simply ask whether oppressive circumstances prevent certain individuals from being able to partake in the benefits of MMT, the relational account I have offered would examine how it is that categories such as IDU or “addict” are organized and regulated by experts, and how participation in the programs are part of the production of contemporary subjects in liberal societies (Rose 1996; Keane 2000; Fraser and Valentine 2008). It might force the question of why take-away doses are so infrequent; whether the universalized response, “it’s because drug addicts are untrustworthy and likely to sell their dose” is appropriate in a given instance; and it would also scrutinize the evidence that supports the universal claim for the pernicious effects of categorization. Relational autonomy isn’t just interrogating whether someone, as an individual or member of a group, has the capacity to be self-determining—it interrogates what it means to be self-determining in a given context as well.
OUTREACH SERVICES

The expansion of HIV treatment in Vancouver’s inner city has been discussed in relation to low numbers of individuals accessing ART in the Downtown Eastside, and the concomitant mortality statistics. Even within this “hard to reach” population, we are told there are reasons to be hopeful: along with simplified, less toxic and more effective HAART regimens, changing treatment guidelines reflect the liberalization of the CD4 threshold for initiating therapy in British Columbia. Moreover, there is an increasingly strong emphasis on the potential public health advantages of ART for reducing HIV transmission at the population level. Cost aversion modeling suggests that the individual level cost-effectiveness that has been demonstrated with respect to HAART similarly applies when considering the prevention of HIV transmission—fewer new infections due to expanded treatment programs is argued to save the health care system money when considering the lifetime costs associated with HIV infection. Treatment expansion (for this community in particular) is increasingly on political agendas and budgets, driven to a great extent by empirical and economic research from BC Centre for Excellence in HIV/AIDS.

A major component of a number of current antiretroviral programs and other health services is referred to as “outreach.” This umbrella term variably refers to the extension of health and social services into the local spaces where “hard to reach” groups reside; outreach services may be delivered by professionals such as nurses and social workers, as well as non-professional employees and “peers.” Early in the North American HIV/AIDS epidemic, outreach programs directed toward drug users focused on locating those who were not engaged in treatment/recovery programs, and provided them with prevention counseling in an effort to get people “to eliminate or reduce their risky behaviours” in order to prevent the transmission of HIV/AIDS (Coyle et al 1998, 20). Current programs are directed toward an increasingly wide range of health and ancillary services, including medication administration, accompaniment to
appointments, wound care, and in some instances, assistance with activities of daily living. Two community clinics in the neighbourhood offer some form of outreach as part of their maximally assisted therapy (MAT) program for HIV/AIDS treatment; in one clinic this service is strictly for those in the MAT program, while the other clinic extends outreach to those who are HIV-infected, whether or not they are currently on treatment. Home care nurses who provide daily HIV/AIDS medications (among other nursing services) to patients are also part of an “outreach” model. Other health authority programs have been developed in recent years to expand outreach programs; “roving” teams of health care providers visit particular housing units and SRO hotels on certain days of the week, in order to locate individuals who might need medical care or follow-up after a recent hospital admission.

There are important challenges that outreach programs need to contend with, given that the programs are undoubtedly an extension of the medical system into individuals’ otherwise private spaces. Depending on how outreach services are conceptualized, this can mean that the programs are sometimes experienced as invasive and controlling, or it can mean that they offer a supportive network to systemically disadvantaged individuals. One outreach worker, commenting on the “explosion” of outreach programs in the Downtown Eastside, suggested that the differences between the programs are vast. Some set goals guided by the individual clients/patients who participate in them, others determine receipt of outreach services according to those who will abide by the program rules; some offer services to those who will be in a particular location at a particular time, others have flexible schedules for employees so that participants in the programs determine their own particular courses of action.

Nurses in the community suggested to me that some outreach services were merely an extension of the clinic into a person’s home, structuring the treatments offered according to the standards of the medical system and needs of staff. Describing the variability amongst one downtown outreach team, a nurse described one of her colleagues saying, “[the other nurse]
says, “no I’m not playing that game.” That game being knocking on the door, seeing if he’s there, giving him his meds.” When individuals are not at their room when an outreach worker or nurse comes to provide pills or to take them for an appointment, they are seen as not wanting to participate in the program; when they request that the dressing change take place in 20 or 30 minutes, they are seen as being difficult. When this happens repeatedly, they may be removed from outreach programs altogether. Talking with me about HIV outreach programming, a community family physician stated, “it takes my breath away when I hear “well she didn’t make her appointment therefore she’s not on our program anymore.” Difficulty partaking in care may be understood by employees to reflect the patient’s irrational but nonetheless personal “choice.” This is a form of outreach based on the liberal normative framework that I have argued against.

Problems of this sort are often addressed by feminist accounts of autonomy, by way of giving substantive criteria for autonomous agency. Most feminist views of autonomy would inquire as to social, economic and political conditions that shape an individual’s capacity to participate in the outreach, logistically as well as in terms of their motivations and preferences for health care services. But as my earlier discussion suggested, it will not suffice to stop at an interrogation of why certain individuals have a hard time accessing the program. The challenges of remaining engaged in care, and the terms upon which outreach services are negotiated between patients and providers (if they are negotiated at all) need also to be investigated, and most feminist accounts would do so adequately. Two nurses, critical of certain tendencies in outreach programs, offer assessments that I take to be consistent with the concerns most frequently examined by feminist theorists:

Nurse 1: [the health authority] sets up these “silo” teams that don’t really communicate, shove them in to these places, and that’s it. [Programs] are not seven days a week, they don’t do HIV, don’t do meds. It’s simple wound care and diagnostics...to a point.

Nurse 2: [the outreach programs] are Monday to Friday. And they’re in the hotels. One of the nurses [had said to me] “Oh Tina...there’s this wonderful nurse in the building,
he could give [the pills] to her.” Well, (a) they’re not seven days a week, (b) she doesn’t know him from Adam, and (c) when she’s up in Yaletown for three days or out in the alley, they’re based in the hotel.

The nurses described that they were both concerned that this sort of outreach model tacitly promoted a very constrained approach to care in the inner city community: they operate independently of other health services and emphasize a limited range of medically-oriented tasks (e.g., wound care), failing to holistically address a particular patient’s health needs. Likewise, the services are oriented toward specific locations rather than specific individuals—the patients within a given building seem as though they might be interchangeable. A constitutively relational account is able to offer the conceptual resources to criticize programs that are oriented in such a way, while also generating novel insights by asking whether and how participation in outreach programs is generative of a kind of person and a regulative force within contemporary western medicine, materializing certain subjects in particular ways.

Along with the questions listed above, a constitutively relational account also offers a set of considerations that focus on what it means to have a dialogical engagement with others. Instead of structuring outreach services according to biomedically defined tasks that have specific billing codes and can be ticked off on a checkbox, outreach might be less dominating and invasive if it were oriented around an understanding of how responsible advocacy practices might be undertaken, enabling possibilities of autonomy for those in dependent positions. Lorraine Code defines advocacy practices as representing, arguing for, recommending, acting or engaging in projects of inquiry and intervention in support or on behalf of someone or some group of people (Code 2006, 169; Code 2000, 185). Although Code warns that there is always a possibility of paternalism and unscrupulous guidance, she also states that, “these practices, I propose, are integral to the very possibility of developing an instituting social imaginary that is capable of promoting social conditions of cohabitability in the best sense…” (Code 2006, 169-
In their most appealing form, advocacy practices are one way that novel intersubjective meanings can be generated and non-subordinating forms of mutual recognition fostered.

Responsible advocacy practices depend “on a vigilant and sensitive ethical stance vis-à-vis the encounters, debates, consultations, or lobbying they may generate, to guard against abusive/coercive paternalism by preserving and respecting self-reliance where it is reasonable to expect it and working to foster it when it is not” (180). Here we have a different way for health care providers and researchers to approach what it is that they are doing. A dialogical model breaks down disenfranchising divisions of intellectual labour and expertise (188) and understands its own ambitions self-consciously so as to attempt to refrain from reinforcing negative tropes and images attached to those who require advocating for. By engaging with a dialogical model of the self, and using that model to inform a discussion of possibilities for autonomous agency, Code’s analysis gestures toward the ways in which a relational account of autonomy might engender more robust practices of scrutinizing the normative standards that operate within medical practices.45

The discussion of relational autonomy and outreach services signals a different way of thinking about health care engagement and “hard to reach” groups. If we mean to examine social disparities in HIV/AIDS treatment, we can use a relational account of the self and of autonomous agency to start to take seriously the idea that within health care systems that employs a biomedical model, predicated on the normative ideals of contemporary liberalism, there may be challenges to participating in the system because of the colonial framework embedded in it. As my own research has demonstrated, a relational account also provides tools of analysis that render possible a critique of dominant explanations of a lack of engagement in the health system, demonstrating that this is not simply due to a particular set of traits imagined to be associated with the ethnic identity of those who are “hard to reach.” Likewise, we might start to think about the idea that socially and economically disadvantaged individuals have lower
trust in biomedicine, and reexamine the reasons why trust is a barrier to health—it surely is not simply due to deformed affective capacities. Understanding how a lack of trust exists in relation to a normative conceptual framework that structures the space of possibilities for differently positioned individuals, the relational approach can be seen as formally addressing the macro-political issues at the heart of socially based disparities in health.

I admit that trying to reorient the health care system to address the concerns I have raised may not initially improve the phenomenon of adherence, so long as adherence is understood as getting a set of pills into a particular body with a 95% success rate. Good health care requires cooperation, and a mutuality of trust and respect. All kinds of patients do all manner of things other than what their physicians instruct; my empirical data has suggested that this is more likely to occur when physicians operate on a view of their patients as incompetent, irresponsible, and badly motivated, while simultaneously seeing their own viewpoint as factual and value-neutral. With that in mind, my analysis does have something to say about the lamentable patterns of non-adherence—that those whose ascribed social identities are the most maligned in society are also the individuals who are most disenfranchised from the benefits of medical research and care; I contend that this disenfranchisement cannot be satisfactorily understood by a framework that holds its own normative standards beyond scrutiny.
CONCLUSION
SOCIAL IDENTITY, AGENCY AND THE POLITICS OF ADHERENCE

“The future of reality is always at risk in a sea of uncertainty” (John Law 2004)

In an expansive approach to the phenomenon, I have tried to say something about social, economic, individual, medical, and political processes that constitute adherence to antiretroviral therapy. Refusing to take either identities or pathologies as “given,” my empirical study has demonstrated various contingencies of HIV-related pathology, partial perspectives that make up adherence, and how normative conceptual frameworks mediate these through value-laden criteria for rationality, agency and identity, without necessarily appearing to have done so.

The received view of autonomous agency, based on a liberal conceptual framework, tells us that an essential feature of human agency is the capacity for action to be informed by reflective self-evaluation. My re-framing of adherence suggests that while agency is first and foremost about action, actions, along with the self that is doing the evaluating and acting, are constituted within and through a situated context. This context is material, social, and importantly, historical. Past experiences, other’s memories, the instituted imaginaries of one’s culture, etc. structure conceptual apparatuses that make it possible to intend, and thus possible to do. Whether endorsed or not, the content of socially constructed “kinds” of people feed back to inform self-identities, in a way that has potential to influence meanings attached to ingesting medications, remaining in, or removing oneself from, healthcare institutions.

Enacted at an interpersonal level, agency is shaped by categories that are deployed within larger systems of HIV care and research. As the normative structure of liberalism and biomedicine are internalized, those who fail to achieve its standards are further marginalized from its promises of an encompassing centre of privilege. Docile as well as self-governing and gracious bodies “access” health and are accounted for by various surveillance measures, further dichotomizing patients as “good” or “bad,” “healthy” or “sick.” Because negative agency in
particular is set against a norm of compliance, identities can become entrenched, and the political economy of liberalism embodied as pathology. This feeds back into process of producing medical knowledge and the formation of individual identities, objectified through population-level data. Statistical methods attempt to identity who receives the majority of treatment effects by way of risk stratified analysis; these methods presume that researchers have adequate information concerning “risk” and the characteristics that confer it. My discussion of looping effect indicates that risk categories may seem like neutral, descriptive terms, when in fact such categorization often has the effect of constituting groups based on these terms. Medical research and practice may thus have the inadvertent consequence of further entrenching constructions of HIV positive women as deviant, dangerous and/or irrational.

My own approach to researching adherence to ART has been to move beyond the boundaries of the conventional picture and, through interpretative and iterative processes, examine narratives of differently positioned agents so as to create novel objects of knowledge and to bring different realities forward. Inevitably, the process of pinning down certain phenomena allows others to escape. Valentine and Fraser, writing of the manner by which research methods have a constitutive role in reality, explain:

[method] creates presence. In the process, it also creates manifest absence (those things manifestly excluded) and Otherness (those things excluded and suppressed so that their absence is invisible, unimagined, unthought). (Fraser and Valentine 2008, 29)

One of the benefits of relational approaches to theorizing and researching autonomy is its basis in a dialogical mode of engagement and emphasis on intersubjectivity. I have argued that this model has a capacity to open up novel ways of thinking about problems in HIV/AIDS care, while remaining attentive to roles that normative structures and invisible assumptions concerning the biological as well as the social have to play in constructing the reality that is under investigation. A dialogical model envisions research as attempting to conversationally expand a set of ideas through both giving and taking of information from mutually situated knowers,
fostering participation in the social activities of knowledge production. The dialogical model is by no means beyond scrutiny; it only wears its normative presuppositions on its sleeve.

THE POLITICS OF CRITIQUE

I hope that it is apparent that the critically informed discussion I have given has not launched us into an utterly nihilistic and skeptical deconstructive mode. At the end of the day, feminist theory is about politics, and needs to be able to have a position from which to speak. One of my ambitions in attacking the logic of the Subject | Other binary has been to express the urgency and cogency of critiques of liberalism that arise from positions of difference, while avoiding the reactionary swing to its opposite: what Didier Fassin evocatively described as “political anesthesia” (Fassin 2007, xii). Political anesthesia is a form of radical “othering,” which results in an acceptance of taken-for-granted explanations and a failure to continue to press on the boundaries of common sense when contending with issues infused with challenges of difference. When partial perspectives are taken to represent a transcendental worldview, it can serve to mark off an unassimilated Other as incommunicable, and social worlds as incommensurable (xiii). My project has attempted to reveal how binary logics are implicated in the constructedness of incommensurability, and how an alternate mode of engaging with others in the world might open up different conditions of possibility for agency and identity. It is within conditions of possibility that feminist politics operate.

Along with the attention that I have given to ways in which possibilities for women are shaped within and through common adherence facilitators such as directly observed therapy and methadone maintenance, I have suggested that different approaches to engaging women in health care services may variably reproduce problematic standards of liberalism in biomedicine. When programs merely replicate dominant conceptual frameworks—of rational actors and liberal autonomous agents—modes of agency that include patients taking themselves out of the institutional structure are enacted. But individuals are obviously not removed from imaginative,
moral, or epistemic structures of biomedicine and contemporary society more widely. So long as the conceptual and normative resources predominantly employed within HIV/AIDS programs remain attached to the precepts of liberalism, a constrained space of possibility will overdetermine particular Others as imagistically and materially pathological.

UNIVERSAL RIGHTS AND THE EXPANSION OF ART

Conceptual and normative resources of liberal frameworks include discourses of universal human rights. In the context of access to HIV treatment, thinking about universal human rights is not particularly novel, and so it should be no surprise that this popular rhetorical tool of contemporary liberal thought finds its way into discussions of HIV treatment in Vancouver’s inner city. As increasing calls to expand testing, surveillance, and treatment for HIV/AIDS echo through clinics, health authority offices, and research centres in British Columbia, we might ask what various considerations raised by my project would have to say about the use of universal rights rhetoric in the arguments for expanding treatment services, for example, through programs such as the STOP HIV/AIDS proposal initiated by the BC Centre for Excellence in HIV/AIDS.

The proposal sees a patient-centered focus of access to HAART converge with a population-based prevention focus on a number of axes. Along with individual health benefits of ART, expansion of therapy is championed as a way to prevent transmission through lowered “community” viral load and to provide a cost-savings to the province, both through treatment of infected persons and prevention of transmission (Montaner 2009, presentation to BCCDC). The justificatory schemas seem to demonstrate convergence of sound ethical, clinical, and economic interests. In Downtown Eastside Vancouver, recognizing relationships between health and human rights for people living with HIV has translated to a call to expand testing, outreach services, harm reduction, and supervised therapy programs. As public health ethics continues to engage with rights-based ethical frameworks, the rapid expansion of HIV treatment appears to be an intervention that is coherent, rational and good—and an
ideal exemplar of the utility of a rights framework for public health, and liberal ideals at their most emancipatory.

But my work throughout this project has argued that contending with HIV/AIDS treatment rates in the Downtown Eastside community isn’t merely an issue of having more individuals tested for HIV infection and given medications. Nor even is it about having more outreach programs operate in an ever-increasing grid of health and ancillary services. As one physician said to me, all of the people who are straightforward to test and treat have been tested and treated. He felt that for those who are not receiving the benefits of therapy, the issues go well beyond HIV/AIDS itself. I have argued that some of those issues have to do with dominant modes of engagement between individuals constructed as Other and the health care system’s biomedical model and liberal humanist framework.

Individual rights are affirmed within a masculine code that is also tied to wealth—rights, historically, have been granted on the basis of assets, and organized to govern the relationship between competing property claims (Rawlinson and Donchin 2005). Different identities do exist—children, the mad, workers, women—but they have been defined by the terms of the ideal masculine subject and hierarchized with respect to him (Irigaray, 1985). Expanding the scope of rights to include those who don’t own property, aren’t autonomous, etc., fails to change the singular subject because the universal is idealized as a rational male actor. Those “Others” who historically did not have access to rights, do not eradicate this hierarchy simply by making a rights claim—they are still defined in relation to an idealized universal subject. Using “rights talk” certainly serves a political purpose—it can mobilize government support for programs, for example. We are left with expectations of outcomes related to a singular masculine subject. But there’s a further problem. The power of rights rhetoric is that its deployment has a profound ability to shut down critical debate; rights talk radicalizes its opposition.
Critical debate about why programs aren’t working is limited, insofar as those who offer dissenting views appear as though they don’t “support” human rights or expanded access to ART. As both Terence Turner and Catharine MacKinnon point out, rights are not simply constructs—they are normative formulations that shape social action. Within this project, I have attempted to demonstrate how rhetorical frameworks, which become embedded in research practices, health programming and policy, have a way of excluding and suppressing certain actions and objects of knowledge, such that certain problems and their solutions remain unimagined. Until a different model of health care engagement and practices of knowledge production are instituted, patients who are “difficult” will continue to evade the productive power of contemporary biomedicine and identities associated with individuals categorized in opposition to an unstated normative standard will be ever more sedimented and stable, appearing simply to reflect the reality of nature.

I suggest that we think about putting politics back into health. Let us focus on historical and material determinants of health, not simply psychosocial determinants. Let us also step away from polarizing debates, where the right and the good line up behind a seemingly unified science. My own research suggests that we might focus specifically on how micro-networks of power shape people’s experiences in the health care system—phenomena that are inconsistent, minute, and full of inherent tension—things that totalizing discussions and generic research instruments are inattentive to. If so-called difficult and disruptive patients are the ones who are least likely to participate in witnessed ingestions or have their methadone linked to ARVs, we need to ask, “what makes someone ‘difficult?’” We need also to ask ourselves what it would look like to have HIV care shaped by a cacophony of voices, to work within the complexities and tensions that exist between care givers and receivers, rather than roll out models and evaluate them with blunt statistical and rhetorical tools, capturing only those who make themselves available to measurement.
NOTES

Introduction

1 The document focuses on the harms of substance abuse, with funds directed toward the four pillars of prevention, treatment, enforcement and harm reduction, in an effort to address “the urgent and complex social, economic, and health and safety issues of the Downtown Eastside” (MacPherson 2001).

2 The series was run under the title “Canada’s Slum: The Fix,” and initial articles appeared in the Focus & Books as well as British Columbia sections of the Saturday edition of the Globe and Mail (February 14, 2009). The series ran additional articles on February 23, 2009, March 2, 2009 and March 8, 2009. The reference to a “Czar” reportedly comes from Police Chief Jim Chu in his report, Project Lockstep. Gary Mason endorses the idea on the grounds that an overarching vision for the neighbourhood is needed, but writes that the position is unlikely to materialize because of the politics between agencies, poverty groups and activists. Mason’s discussion fails to note the problematic elitism of the Czar position, and the rash determination that the “special interest” groups and activists lack credibility—Lorraine Code identifies this sort of thinking as a kind of oppressive epistemic practice in her analysis of advocacy and epistemic autonomy. Advocacy practices are often denigrated on the basis of their presumed lack of objectivity; this position is based on the notion that objective inquiry amounts to random fact finding and knowledge production as demanding expertise and individual autonomy. In Miranda Fricker’s work on epistemic injustice, Fricker similarly identifies that, historically, determinations of objective knowers have been based on status and privilege, due to the idea that such individuals do not have vested interests in outcomes because of their social standing. I take up these issues in chapters 4 and 7. See Fricker 1998 and Code 2006.

3 In a striking parallel to the rhetoric of the chaotic drug “lifestyles” in the downtown eastside, critics of Bill Vander Zalm’s Social Credit government (1986-1991) have referred to the social policy making at that time as “chaos without style or substance.” Figuratively, at least, I take this to be a signpost of a connection between the historical elements of health politics and the current social field, as it now exists. The policies and politicking of that time bears the pathological fruits of tomorrow: the legacy of the “restraint” era and overhaul of health services are (for better or worse) inscribed on individual bodies, and picked up at the population level by the surveillance of infectious disease trends.

4 Dara Culhane and Leslie Roberston make this point in their introductory remarks to In Plain Sight (2005); See also, Culhane 2003.

5 Susan Sherwin makes a similar point in her critique of conventional ideals of autonomy. She argues that autonomy language hides the workings of privilege; it feels natural for people raised in an atmosphere of privilege to think of themselves as independent and self-governing because they are in many ways oblivious to the barriers of oppression and disadvantage as well as the social arrangements that support their own sense of independence, such as education and a relatively high degree of personal safety. They need only “apply themselves” to succeed, because there are few impediments or roadblocks to their achievements, and many more facilitators. Their successes seem self-created and deserved, while others’ failures seem individualized and reflective of irresponsible or non-judicious behaviour. I take up this point further in chapter six, drawing on Naomi Scheman’s related analysis. See Sherwin 1998, 25.

6 This set of judgments is part of what Martha Minnow refers to as the “dilemma of difference.” One side of the dilemma is soft culturalism: there are negative consequences when institutions affirm the value of difference (as in policies granting special status or consideration), insofar as “Otherness” is symbolically reinforced and the ire of the dominant group is raised against those receiving “special privileges.” On the
other side of the dilemma is the issue of universalism: merely tolerating difference and striving to treat all as equal under the guise of impartial reason may reinforce past injustices while presuming that the interests of the excluded can be assimilated to those of the dominant group. For a discussion of this, see Meyers 1994, especially Chapters one and two.

7 Foucault uses the term “pastoral power” as a way to articulate the historical congruity between the pastoral power embedded in Christianity and its spread and multiplication outside of the ecclesiastical institution, to those of the state (schools, clinics). The term refers to power held by those who are charged with the responsibility of ensuring the spiritual (and then later physical and intellectual well-being) salvation of a flock/population. Historically, this has been the imagined role that Anglo colonial administrators have likewise held for themselves. Foucault describes a shift in the 18th century, whereby pastoral powers were simultaneously individualizing and totalizing, as the knowledges of citizens became co-produced through medicine, hygiene, welfare societies, policing, etc. (784). Large population-based quantitative studies work with the analysis of individuals in a way that fashions the subject through simultaneously individualizing techniques and totalizing structures (782). On the individualizing arm, the pastoral power is charged with ensuring the salvation/well-being of each individual as an individual by way of knowledge of the inner depths of each person’s consciousness (Foucault 1982, 782-784). Purification and salvation requires that one examine one’s own self—thoughts as well as intentions and even the smallest movements of consciousness (Foucault 1988). There is a connection to technologies of the self that is yet again extended in late modern societies: the urging of responsibility, self-governance, and risk management is extended to the expectations of citizens themselves, and enforced through normative frameworks such as that of autonomous agency. For an interesting discussion of the relevance of technologies and care of the self for bioethics, see Murray 2007.

8 I use these terms as they are given by Mary-Ellen Kelm, in her discussion of Aboriginal Health in British Columbia through the first half of the twentieth century. See Kelm 1998, especially Chapter 6.

9 Following the language used in surveillance and census data, the term Aboriginal is used here to indicate individuals self-identifying as First Nations, Inuit, or Metis.

10 Due to differences in reporting of ethnicity, the 2007 PHAC HIV surveillance data notes that the percentage of HIV positive women amongst persons of Aboriginal ethnicity is restricted to those provinces that report ethnicity. This does not include Quebec (PHAC, 2007).

11 “HAART” refers to the use of at least three antiretroviral medications in combination with one another (and often, an adjuvant or booster medication). “ART” refers to antiretroviral therapy: in the vast majority of cases, these are the same thing (i.e., patients are no longer given monotherapy or dual therapy because of problems of drug resistance). I therefore use the two interchangeably; in instances where they are not interchangeable, I make specific note of this, and use the term “ART.”

12 Projections of HIV prevalence amongst injection drug users in Vancouver for 2006 were 17% (McInnes et al., 2009).

13 Average annual incomes are consistently below $15,000 CAD; the Downtown Eastside Residents Association (DERA) reports that the majority of residents live below the poverty line, spending more than 45% of their monthly income on housing costs.

To cite an example of the significance of research honoraria to individuals’ incomes: I was conducting observational research with a team of nurses in the community one morning during the summer 2008, and a consultation took place with one of the women who is infrequently on the nurses’ roster, but who is seen by a physician in contact with the nurses. The nurses spoke with the woman, who was concerned about her upcoming doctor’s appointment at which she was meant to receive her weekly methadone script. She stated to them that there was no way she could make the appointment the next day, as it would take too long, causing her to miss part of her research meeting, thus she would only receive a portion of the honorarium rather than the whole thing. She said to the nurses that they would have to tell [the doctor] that she couldn’t make it, she’d have to forgo the methadone script and “just use heroin for a couple of days” until she could see the doctor again.

The main cohort studies are: the Vancouver Injection Drug Users Study (VIDUS), Community Health and Safety Evaluation (CHASE), Scientific Evaluation of Supervised Injecting (SEOSI), and the Maka Project. The Bart and Homer cohorts have been created from the DTP sample database, and are generally discussed with reference to VIDUS. The discussion I am giving in this chapter references primarily (although not exclusively) the access and adherence literature related to the cohorts listed above. Additional sources include smaller studies based on data from focus groups held at the John Reudy Immunodeficiency Clinic (“IDC”) at St. Paul’s Hospital.

For example, surveys will ask participants about the frequency of cocaine and heroin injection using the same time intervals as response options, and define for the purposes of analysis “frequent” drug injection in the same manner (once or more per day), thereby enabling comparisons in time (within the same cohort) or across cohorts.

See, for instance, Rachlis et al., 2008. The authors discuss issues of IDU access to treatment, prevention programs, etc. within North America, referencing primarily VIDUS data, the same cohort they analyze in their study, while stating in the discussion that the VIDUS cohort is not a random sample and therefore ought not to be used in generalizing to the wider IDU population.

Kerr et al., 2004 report that no socio-demographic or drug use variables were associated with HAART adherence (variables include: male/female sex, unstable housing, sex work, cocaine/heroin frequency and so on) for VIDUS cohort members, while other discussions of adherence suggest that it is because of adherence problems that IDU in the VIDUS cohort do not achieve suppression, linking the category “IDU” with non-adherence; this link has been reinforced by other adherence studies in the community (e.g. Shannon et al., 2005). Regardless of which variables become independently associated with adherence, concluding statements reinforce the following ideas: drug users are unable to maintain themselves on ARV therapy unassisted; addiction management (e.g. methadone maintenance) ought to be tied to ARV use; further research is required for this population. See Elliott, 2007 for an in-depth discussion of this issue.

One nurse on a ward at the hospital that generally provides care to inner city residents was surprised to learn that her patient, who is part of the study, had an address at all, saying, “it just says D-T-E-S on the chart.” She didn’t, apparently, feel the need to inquire any further.

One woman who resides in supported non-market housing, but whose address had simply been marked “DTES” on her medical chart, described an encounter with a hospital addictions specialist to me saying, “I said to him, ‘what are you looking at?’ He was looking for track marks! I don’t know how many times I’ve told him I don’t inject. ‘Goosebumps’ he says. Yeah, right. Looking for goosebumps.”
Sex work is a challenging variable to study, but is included on each of the cohort surveys. Women who inject drugs are inevitably surveyed about their participation in the sex trade even though women in the sex work cohort preferentially smoked crack cocaine and many women who occasionally exchange sex for money or drugs do not consider themselves sex workers.

On numerous occasions when I’ve been in the community with women participating in the research study they have loudly berated men for staring or making sexual comments toward me, saying “she’s not for sale,” and telling me that the men figure I’m “fresh meat” because I look clean (i.e. not using); Fairbairn et al. (2008) also describe how women are ‘grinded’ in the street setting because of the general assumption that they are likely to be in possession of money or drugs since they are able to make money as sex workers, whether or not they actually do. The assumptions about participation in the sex trade extend beyond the borders of the neighbourhood. At the hospital as well, I at times heard casual comments about women “selling themselves” or being “sex trade.” On one occasion this occurred with a woman I knew personally to be dealing drugs and not involved in any sex work.

Significant attention has been paid to psychosocial determinants of adherence, particularly self-efficacy constructs and education regarding the benefits of medication, the inability to integrate treatment into the “chaos” of daily life with addiction, and an inability to manage side effects. Interventions focus on establishing readiness to adhere, as well as assisting with skill development, self-observation, and extending clinic hours to accommodate binge patters of drug use.

Each of these are examples of what Leslie Robertson describes as a system of colonial legislation in Canada (Robertson 2007). The residential school system forcibly removed Aboriginal children from their home communities and placed them in residential schools where physical, emotional, and sexual abuse was common and English strictly enforced; court testimony and media reports have made evident the intergenerational effects of the policies of abuse, mistreatment, humiliation, and loss of language and cultural tradition (Royal Commission on Aboriginal Peoples 1996; see also, Browne and Fiske 2001). A large number of schools had closed by the end of the 1960s, though the last federally run residential school did not close until 1996. For a history of residential schools in Canada, see the Assembly of First Nations page: http://www.afn.ca/residentialschools/history.html

*Terra nullius* literally means an unpopulated land or territory. In British Columbia, the settlement patterns arguably followed this definition, insofar as the provincial settlements were established on the thesis that the territories were unoccupied and/or did not belong to another political entity. Indigenous sovereignty was not recognized and as such, Indigenous persons were not presumed to have title to property under law. Across the country, the 19th and early 20th centuries saw an expansion of the reasons for denying title, and the inconsistent and ultimately illogical reasons served to justify reserve systems and residential school policies, as well as the long-standing refusal by the provincial government to hear or negotiate land claims. For a review of *terra nullius*, see Asch 2002.

This acronym refers to “men who have sex with other men.”

A large body of compliance/adherence research has stemmed from the now-classic text, *Compliance in Health Care*, eds. Haynes, Taylor and Sackett. The editors provide the definition of compliance as the extent to which a person’s health-related behaviour coincides with medical care or health advice—a definition which subsequently came under criticism for being overly oriented to the perspective of health care providers, and for presuming that medical advice was rational and any deviation from it problematic.

The provincial government of BC has promised $48-million over four years for the “Seek and Treat to Optimize Prevention of HIV and AIDS” program (STOP HIV & AIDS), which aims to curb transmission...
and present AIDS-related morbidity and mortality through the expansion of HIV treatment to hard-to-reach residents in Prince George and Vancouver. In personal conversations with researchers and clinicians affiliated with the BC Centre for Excellence in HIV/AIDS, proposed plans to scale-up treatment were described to me to likely include outreach positions, maximally assisted therapy programs (which include directly observing therapy) and may possibly include incentivization of treatment.

29 See, for example, Margrit Shildrick’s “The Critical Turn in Feminist Bioethics.” Shildrick 2008.

30 By this, I mean to suggest that philosophical work in public and population health ethics has yet to engage substantively with post-modernist and post-structuralist insights, particularly those from the fields of medical anthropology and medical sociology. I note some exceptions to this, particularly the work of Margrit Shildrick, Carl Elliott, and Stuart Murray.

Individuals working in medical anthropology and sociology often do engage with the normative and ethical implications of their work, but with respect to public health ethics as a branch of applied philosophy, there is a decided lack of dialogue between disciplines. The prevailing theoretical frameworks within public health follow rights-based constructs, which sweep past post-structuralist thought, endorsing the liberal philosophical constructs that dominant mainstream bioethics. See Donchin and Rawlinson for a good discussion of this (2006). One might also suspect that there are epistemological factors underlying the lack of connection between public health ethics what is generally an anti-positivist orientation to post-structuralism and post-modernism, given the widespread use of epidemiological methods of study within public health practices. I address this issue further in Chapter 2.

Chapter One

1 Strathdee et al., 1998; Shannon et al., 2005; Holzemer et al., 1999; Tuboi et al., 2005, Nicastri et al., 2007 HIV/Antiretroviral Update, 2008

2 For clinical purposes, adequate adherence is defined as the level of adherence required to sustain suppression of plasma viral load below 50 copies/mL. Rates of >95% adherence are reported as meeting this criteria while maintaining sufficient plasma drug concentration to prevent resistance to ART (Stone, 2001).

3 Taking the view of why someone might fail to engage in health may, for example, ignore the structural challenges that exist for those within the health care system, and the reasons for their being there. In chapter six I argue that difficulties navigating institutional bureaucracies, which can be the result of social and material disadvantage, have a tendency to reinforce negative images attached to certain groups, particularly when those images contravene norms of the ideal agent. Patients who are in a disadvantaged position may be seen as difficult, fickle or manipulative if they fail to follow through on health-related intentions, which are taken by those who don’t face systemic disadvantage to be straightforward and relatively simple to achieve. Emphasizing barriers rather than the quality of health care interactions ignores the impact that such negative images have on quality of care and on treatment follow-through, especially when it’s the case that these influence some aspects of care (e.g. follow-up appointments with specialists or medication use) but not others (e.g. emergency room use or general primary care).

4 In reviewing the epidemiological literature surrounding access to services in the downtown eastside, I note that there are some exceptions to this statement. Increasingly, attempts have been made to situate epidemiological studies of the neighbourhood within a larger body of qualitative and geographical information system literature. For example, in Shannon et al., 2008, the authors analyze the distribution of health and needle exchange programs in the community against the distribution of police activity and
locations of violence, linking this rhetorically (though not analytically) to issues of meaning and signification. Quoting Rhodes et al, 2005, they write, “built environment is defined by both the social and physical meanings ascribed to place, such as the meaning a drug user attaches to a place due to previous adverse interactions with police.” But the research itself remains locked within a causal explanatory framework as well as maintaining an emphasis on the need for individual level data to determine statistically significant factors. I note here that neither the mapping data nor their projected individual level of data would allow the authors to determine what meanings might be operating within their location, and will explore the issue of methodology and the determination of meaning in chapter two. At any rate, the reader is left to imagine that a location of violence as such prevents access to services through displacement of sex work locations away from health sites.

5 Kleinman made these remarks in the late 1980’s, when treatment for HIV/AIDS was limited to ineffective forms of monotherapy, if any treatment at all (a single antiretroviral, AZT). Even now, more than twenty years later, there is still substantial evidence that stigma associated with HIV/AIDS has not abated. The issues Kleinman identifies should not, therefore, be taken as obsolete, even as treatment options have dramatically improved, the defining illnesses of AIDS such as wasting are more manageable and the visibly manifest side effects of treatment (e.g. patterns of body fat distribution) are widely resolved.

That said, I will try to avoid using the term “stigma” to discuss negative stereotypes, images and figurations that are applied to HIV-infected women living in the community. This is a decision made in the interests of precision and clarity—my purpose here is to discuss very specific ways in which categorizations inform the content of socially ascribed identities, and the pernicious effects these can have, on health-related action. While it could be discussed in terms of stigma, it is my belief that the specificities are lost by employing this concept, because of its broad and divergent usages as an explanatory construct within a wide array of social science literature. As above, none of this is to say that the experience of being “stigmatized” due to HIV/AIDS does not occur or that it is irrelevant.

6 Clinical environments typically provide a number of necessary social services outside of a traditional domain of “health,” including financial advising, housing support, and other forms of advocacy. Patients are often in hospital, which entails contending with emergency department staff, ambulance attendants, security guards, and nursing and physician staff on the wards, as well as other patients, many of whom also call Downtown Eastside Vancouver home.

7 Quantitative studies that examine “risk environment,” for instance, are generally unable to do more than imply an association with interpersonal interactions. At best, they may link “structural” events with individual-level data that examines subjective attitudes toward particular events. This remains limited in terms of the type of information that can be inferred from the measures.

8 It is imperative for me to note here that I am not suggesting that what my analysis offers is a well-developed discussion of critical social theory. As I emphasize in the Introduction, I am interloping on the domain of medical sociology and critical cultural studies, but without the same disciplinary background and body of concerns informing my analysis as a differently situated scholar would have.

9 For instance, the Vancouver Native Health Society Positive Outlook Program, a drop-in and outreach service, which continues to operate on contract as a non-profit society and the BC Centre for Disease Control Street Nurse Program, initiated by nurses working at the BCCDC.

10 It is interesting to note that for all of the efforts to expand mobile and after-hours services in the community, 2009 has seen the removal of funding for the two most significant access programs – the
Mobile Access Program (MAP) van, run by WISH, a sex-worker support organization and the Downtown Eastside Youth Association Service (DEYAS) van, both of which provide harm reduction supplies, including clean rigs, sterile water and condoms, amongst other services. The MAP van also had the ability to link individuals working in the street level sex trade to health services, and variously had nurses working with the van.

11 As an example, the Framework for Action document identifies the Ministry of Health role as promoting public policy and coordinate HIV/AIDS initiatives, facilitating information sharing across the province, while it is the health authorities that are responsible for planning, funding and administering the delivery of health services (Framework for Action on HIV/AIDS, p. 19-24).

12 The provincial government’s 2001 mandate has been likened to the “restraint era” of the Social Credit party of the 1980’s, in which social services were aggressively scaled back. See MacDonald and Fairey, 2001.

13 Even now, fifteen years after the implementation of health care reform, physicians and nurses identify this same problem. One community physician discussed with me the challenges with coordinating care, given systemic limitation, saying: “there are enough outreach workers, they know to call [us] at home. But if any of those players are gone... so then we end up writing longer scripts for methadone, so that someone doesn’t have to come back when we’re not going to be around, which is itself not a great way to work. But do we do it because what else are we going to do?”

14 These include explicit references in national newspapers, for instance: “They’re Sick of Watching People Die; Just ask the Police and doctors on the front line – harm reduction doesn’t work,” Globe and Mail, July 12, 2008;

15 The reference quotes are taken from an interview with a health care provider, describing differences between physicians and nurses in their approach to medical care for individuals using drugs, which she had experienced working as a physician in one community clinic.

16 Citing Blumberg et al. 1971, Kemple and Huey discuss how “skid row” neighbourhoods are civic spaces, emerging from the interstices of business districts, police wards, transportation centres, etc. but nevertheless geographically and morally excluded (and contained) from the activities of the so-called general public (Kemple and Huey 2007). Thinking specifically about the relationship between economic and moral exclusion, it is helpful to look to Loic Wacquant. Wacquant describes the interconnection between spatial stigma and advanced marginality, as “fed by the fragmentation of wage labor, the reorientation of state policy away from social protection in favor of market compulsion, and the generalized resurgence of inequality—that is, marginality spawned by the neoliberal revolution” Wacquant 2009, 115; original emphasis.

17 I note that the downtown eastside is not ethnically homogenous, one characteristic of a ghetto that Loic Wacquant is quick to point out is critical for the very notion of ghettoization.

18 Insofar as they maintain the underlying liberal humanist view of autonomy, I will refer to such attempts as “conservative” accounts. Examples of attempts to re-draw the boundaries of autonomy, while preserving the qualities I will later discuss as being problematic. In Chapters six and seven, I employ Cass Sunstein’s work as an example of such an account.

19 There is an alternate form that I am also concerned to distance myself from. This suggests that there are essential differences between those who meet the ideals of agent-autonomy and those who do not,
such that the concept of autonomy as it applies to “Others” must be altered in a way that accounts for these differences. While this may seem like a departure from the standard ontology of autonomy, the conceptualization of difference as *oppositional* is nonetheless part of the liberal humanist narrative that maintains a ubiquitous (white) masculine standard. With respect to relational accounts of autonomy, this means that simply incorporating essentializing discourses into theories of autonomy will fail in its revisionary attempts.

**Chapter Two**

1 Anti-perfectionism refers to the view that political or governing bodies ought not to impose a comprehensive view of the character of its citizens, inculcating in them particular conceptions of the good (e.g. civic virtues). See Sunstein 1991.

2 Susan Dodds, discusses the role of autonomy in medicine as relating to concerns regarding paternalism in medicine, which have grown since the 1970s. This has had the effect of changing the image of the doctor-patient relationship from the presumed beneficent paternalism of the doctor acting on the compliant patient’s interests, to one of a contract between patient-consumer and doctor-service provider; the patient then makes decisions free from influence of the service provider (Dodds 2000, 213). While Dodds goes on to argue that this framing of the doctor-patient relationship has a narrow focus on consent, and constrains discussion of autonomy in health care, I want to emphasize how the presumptions and concerns of liberal philosophy are present in this way of seeing medical care—the notion of two independent agents coming together to contract; the idea that one provides information so that the other can act on their own best interest judgment; the notion that freedom of choice entails non-coercive settings, etc.


4 Shildrick focuses specifically on the consequentialist strains of Utilitarianism and Kantian deontology; I take it as granted that social contract theory is part of the liberal humanist tradition, having been founded by Hobbes, who argued that morality ought not to appeal to god, moral “facts,” or natural altruism. For a good discussion of social contract theory in moral philosophy, see Rachels 2003.

5 My point here is not to appeal to the merits of the principled approach, which is by no means the only way of thinking through issues within the moral and social order of medicine. It is to emphasize that mainstream approach to ethical issues in medicine reflects the ideals of liberal humanism.

6 Lupton argues, rightfully I think, that the rather bleak picture offered by the orthodox view of medicalization does not account for the ways in which medicine is also a productive activity, and patients are beneficiaries of those asymmetries of knowledge/power in various ways. She goes on to offer insights on medicalization from the work of Foucault, specifically the intellectual resources offered by both the view of discipline as well as technologies and practices of the self. See Lupton 1997.

7 Here is the basis for Kant’s famous exclamation, “sapere aude!” One’s freedom (from the pastor, the officer or the tax man) comes from the use of one’s reason in all matters, something Kant describes as requiring courage and determination, but that is nevertheless available to all men. I note that he excludes the “fair sex” from achieving maturity. See Kant, *What is Enlightenment?*

8 Nomy Arpaly also makes this point in her analysis of Oliver Single, the young lawyer in John Le Carré’s *Single and Single*. Oliver is seemingly passive to his actions as he picks up the telephone.
connecting him to Customs, leaving him to expose his father’s illegal activities without having debated, deliberated or reflectively evaluated his actions. Arpaly writes that Oliver is an unusual agent, not at all like the exemplars of agency seen in most philosophical texts. “He is especially different from the person whom we would typically imagine as an autonomous, rational agent…” She uses his case to motivate her account of agency that steps away from the traditional ideals of autonomy. See Arpaly 2003, 3-5.

Normative social meanings, the structural ordering of institutions of knowledge production, values, character ideals, prohibitions, etc. are all aspects of what Lorraine Code refers to as the instituted imaginary of the Enlightenment. Following Castoriadis, Code argues that the view of “human nature” offered within the affluent Western world is an instituted social-political-epistemological imaginary of rational mastery over the external world. See Code 2006, 30-32.

Although I focus to a great degree on the liberal tradition’s emphasis on rationality and the capacity for reason, I do not understand my project as attempting to investigate the problems of “reason.” As Foucault writes in The Subject and Power, such an endeavor traps its interlocuters in “playing the arbitrary and boring part of either the rationalist or the irrationalist” (Foucault 1982, 779). What I intend to attempt, akin to Foucault’s position, is to investigate the specific rationalities that function within a very narrow field—that of HIV/AIDS research and care—in order to locate how asymmetrical relationships of disadvantage and privilege are reproduced at a particular place and time. Again, I am avoiding using the term “power” here for its lack of precision and clarity, and tendency to stand in for a wide range of strategies and processes. If one is to investigate specific rationalities in the manner that Foucault describes, it seems best to avoid jargon and over-determined concepts at the outset of such an undertaking. See Foucault 1982.

I note that Foucault makes this same point in his analysis of disciplinary power, in which he describes the modern state as both individualizing and totalizing. Modern liberal democracies are part of the continuum of political structures whose concerns are oriented around a juridical conception of power, which presupposes an individual who is naturally endowed with rights and capabilities (see Foucault 2003). Onward from the latter half of the eighteenth century, an additional mode of power arose, intertwined with the first. Biopower focuses on the administration of populations and serves a totalizing role. These two arms of power characterize modern social orders. Modern governments are charged with ensuring the flourishing of its populations, in terms of wealth, health and longevity, and employ both arms of power in order to do so (Allen 2008, 56-57).

I take it as given that there are a number of features of contemporary Anglo-American philosophical accounts of agency that are familiar to the reader: agency is about action, intentional action in particular, and the ability to produce effects in the world (including the ability to affect other agents) through one’s actions. Although accounts may vary in their assessment of the metaphysical aspects of agency, such as whether motivation for action is internal or external to the agent, there are central features of agency that are widely shared. Primarily, this includes the capacity to set ends and to deliberate on the means to achieving those, having coherence between means and ends, as well as having the ability to integrate a range of limited or spontaneous ends with those that are temporally extended, such that one does not obviously or immediately undercut the others.

Of course, not all the liberal canon supposes that morality or even action theory requires the notion of a distinct “self.” Notably, on a reductionist view of persons, the existence of a separate entity, distinct from mind and body, is seen as superfluous. On this account, a person is a series of physical and mental events, or what David Hume famously referred to as “nothing but a bundle.” What is of interest, for my purposes, is that even while rejecting that any kind of additional spooky substrate holds together the heaps of experiences and mental states that make up a person, reductionists generally take mind to be distinct
from body. Derek Parfit, for instance, writes that a person is “the existence of a brain and body, and the occurrence of a series of interrelated physical and mental events” (Parfit 1984, 211). What matters for morality and epistemology, even on reductionist views, is mental continuity.

14 Although there are notable exceptions to the generalizations I have made, the emphasis on characteristics or features of rationality as being central to agency are exceedingly common in Anglo-American philosophical thought. For examples of this approach to thinking about agency, see, The Contours of Agency eds. Buss and Overton.

15 This last point is attributed to Scott Anderson (personal conversation).

16 Part of the imagery that has historically justified paternalism has been argued to invoke the notion that the expertise of physicians removes the responsibility of ill-health from the shoulders of the patient (who are not capable of carrying this burden due to lack of expertise), and places them on those of the health care provider, specifically, the physician (Ozar 1985, cited in McMillan 1995, 112).

17 I use the term “authentic” to denote that there is widespread concern regarding an agent’s ownership or authorship of the beliefs and values that are part of their set of ends. This is often seen in what can be called an “authenticity requirement” for autonomy. For an agent to hold authentic values, she must have some belief about the worthiness of those values, she must perceive them as important (such that to act against them would constitute a form of self-betrayal), and she must hold them relatively consistently over time. See Hyun 2001, p. 197.

18 Korsgaard depicts this a pragmatic, rather than substantive, unity of agency. By pragmatic, she means to emphasize that her position does not entail any deep metaphysical commitments. See Korsgaard 1989.

19 In “The Superficial Unity of the Mind,” Sarah Buss examines the notion that persons who do not ensure coherence and connection between their various beliefs lack integrity qua rational agents, for the very sorts of reasons that Korsgaard is worried about (Buss 2006, 316). Buss ultimately argues that most beliefs and values have a level of indeterminacy to them, such that it is not particularly difficult to reconcile conflict beliefs and practices, and indeed the level of unity required to function as an agent is quite superficial.


21 I take it that this is generally the case, whether the self is epiphenomenal or not.

22 For much of contemporary liberalism, this is not a deep metaphysical statement about persons so much as it is taken as a justifiable assumption, given the interest of liberal theories to avoid inappropriate interference on citizens’ values, preferences, aims, and ends.

23 Of course, Buss goes on to refute this view, arguing that the supposed need for integration suggests that there is a workable possibility of dis-unity. If some incoherence is no threat to rational agency, then it is only at a superficial (even trivial) level that this coherence is important for self-preservation. I am persuaded by Buss’s argument and employ it in later sections of my analysis.

24 Even for those who are not working from a Frankfurtean account, integration and unification are taken as significant aspects of agency. The importance of integration is, for instance, the central issue at end within Korsgaard’s discussion of the pragmatic unity of agency.
It is worth noting, even just briefly, that this suggests that integration and unification are embodied processes—Catriona Mackenzie argues this point, describing how bodily changes or processes disrupt the integration of one’s self as temporally extended subjects (Mackenzie 2009, 114).

The ideal of shared decision-making described previously is another indicator that, for most agents who persist with health behaviours, integration of medical information and advice within one’s wider set of traits, commitments and practices is presumed to be an important aspect of medical interactions. In line with this ideal, there has also been a movement within some aspects of medical practice to adopt the language of “concordance” over that of compliance (or its more neutral cousin, adherence). Concordance is meant to be a paradigm shift that is contiguous with shared decision-making, in which the following of medical advice is reconfigured along the lines of consensual agreement between equal parties.

Judy Segal, in a critical examination of the development of concordance discourse in the UK, argues that a close reading of the concordance literature reveals its focus to be about how physicians might persuade patients to follow through with medical advice; that is, concordance reveals itself to be a strategy for compliance (Segal 2007, 82-83). I want to draw attention to the way in which Segal’s analysis of the stated goals of the Medicines Partnership Task Force (Great Britain’s implementation arm of the compliance-to-concordance movement; ibid) highlights that on the “new” view of medication-taking (much like the “old” view), agents must integrate health information and medication beliefs with their other beliefs and desires. From both the compliance and concordance perspectives, patients who take medicines are selves that integrate.

Where certain traits are seen as pre-traumatic, it is necessary to be able to modify these in a way that allows for continuity with the new, post-traumatic self, in order to maintain a set of continuous memories that enable one to see oneself as the same self. This is explained by appealing to empirical data emphasizing that one’s sense of their past may disappear at the point of trauma, and one’s sense of the future is foreshortened due to it. Recovery is therefore thought to require the integration of one’s past, present and future selves in the wake of such events (Brison 2002).

The distinction between positive and negative liberties comes to us from Isaiah Berlin’s, “Two Concepts of Liberty,” in which Berlin defines negative liberty as freedom from coercion and undue interference on private action. Positive liberty, Berlin traces from Aristotle, and is also connected to autonomy. It refers to the capacity for citizens to be part of the process of choosing and endorse the system that governs them. In contemporary usage, positive liberty is thought to require substantive conditions to ensure that participation is possible, e.g., educational systems that are equally available to all. See Berlin 2002.

This might be described as congealing, rather than merely solidifying, the self. See Vogler 1998.

Likewise, indifference to what one values or desires is a mark of wantonness and a failure to meet the standards of personhood (Frankfurt, 1971; 1987).

To that end, we might consider Kwame Anthony Appiah’s discussion of traditional liberal approaches to autonomy, in which he critiques Gerald Dworkin and Joel Feinberg respective evaluations of Stepan Arkadyich, Anna Karenina’s self-indulgent and somewhat vacuous brother. Both Dworkin and Feinberg use the character to emphasize the problems that a lack of authenticity or wholeheartedness posses for agency—Stepan does not reflectively evaluate his beliefs, acting on those—he borrows them from the liberal newspaper, and is incapable of giving an account of their validity or constructing a rationale for his attachment to them (Appiah 2005, 36). When the public opinion changes, Stepan’s beliefs likewise change, albeit imperceptibly to him (ibid). How, the two authors ask, could someone with so little insight and independence of mind, achieve the standard of rational autonomous agency that the liberal tradition calls for? He may indeed carry out acts that are the result of means-end deliberation, but Feinberg and
Dworkin argue that Stepan nevertheless demonstrates agentic failure by having no account of his beliefs being his in an important way.

Appiah gives a valiant defense of Stepan in his discussion of autonomy within the liberal tradition, arguing that proponents of autonomy move too quickly from the human capacity for reflexive self-evaluation and the demand that it be exercised (Appiah 2005, 49). And while I am sympathetic to Appiah’s position, the example certainly indicates how common-place the relationship between reflective deliberation and liberal conceptions of autonomous agency is understood to be.

I note that Oshana is interested in asserting that there may be a subset of cases in which wantons are properly held responsible for their actions, in spite of their failure to reflect on and endorse their lower-order desires. But for my purposes, her arguments are valuable in emphasizing the characteristics of those wantons who Oshana agrees are not agents.


In a recent edition of Bioethics, Grant Gillett examines this usual interpretation of autonomy as a form of self-rule that follows a means-end reasoning process, suggesting that the emphasis on internal reasons (beliefs, desires, states of mind) seem to produce the unsettling idea that rational conscious choice is an illusion, given that brain events are not under rational control (Gillett 2009, 311). The notion that inner processes (e.g. nerve pathway signaling cascades) are the “real” causes of human action is problematically reductionist—as Gillett argues, human action is more often a result of a subject engaging in a “dynamic flow of discursive activity reflecting and influencing his/her thinking in a holistic flow” (333). In Gillett’s words, decisions are not circumscribed events in neuro-time (ibid). For my purposes, Gillett’s discussion is useful in pointing to the problematic vision of behaviour and rational action that is offered in the conventional accounts of adherence. Gillett’s discussion applies to my own concerns regarding adherence and behaviour: while internal brain events are not irrelevant, they are not definitive of rational agency. Paradoxically, it would seem that conventional adherence accounts are vulnerable to the sort of mistake that Gillett is worried about, that they seem to generate the “unsettling” view of the impossibility of autonomy, even while lauding the very typical accounts of autonomy as rational action.

A substantial body of philosophical literature concerning the concept “trust” posits trust as an attitude (rather than a property) that depends to a great deal on accepting a level of risk or vulnerability to betrayal. I am making the relationship between trust and confidence on the grounds that trusting requires the belief or optimism that the trusted individual is competent in certain relevant respects (see Mcleod 2006; “Trust” in Stanford Encyclopedia of Philosophy). Although this condition is accepted as necessary for trust, it may not be sufficient. Nonetheless, for my purposes what matter is that trust may be one significant aspect of “confidence” when thinking about adherence to medical advice.

It is important to draw attention to a distinction between the view that those who are privileged are those who frequently enjoy a dominant subject position within an opposition dichotomy, and the view that those who are receive benefits of social privilege are statically dominant. The former engenders a view that positioning is not stable or timeless, and is contingent on social location and relations to others. A Caucasian woman might find, for example, that she receives the benefits of certain forms of privilege in virtue of her whiteness, but that she is disadvantaged along a different axis of identity, in light of the privileging of masculine versus feminine identities. I am taking up the view expressed by the former aspect of the distinction I have drawn, which is a distinction frequently employed within standpoint epistemology and intersectional theories of identity. See, for example…

I explore this more thoroughly in Chapters five and six.
I would be remiss to ignore how Habermas’ critical theory is both a part of the liberal humanist tradition and as dialogical. Much like the liberal accounts I’ve been detailing in this chapter, Habermas’ notion of autonomy tends to relate freedom with the capacity for reflexive distance from social norms and rational accountability. His account of communicative action sees the development of social norms as intersubjective and dialogical. Amy Allen offers a thorough and insightful discussion of the limitations of Habermas’ dialogical model, arguing that the reliance on a notion of validity as context transcendent undermines the critical capacity of the theory, and edges it closer to conventional liberal accounts.

I have chosen to emphasize the significance of monological versus dialogical models for epistemology rather than for language/communication. This is not meant to indicate that they are so vastly distinct, nor that communication holds a less significant set of considerations for agency and the self. As Allison Weir emphasizes, the problem of identity of the self is bound up with the problem of identity of meaning, and with identification or relationships with others (Weir 1994, 189). For the purposes of clarity and rigor of analysis though, one can only attend to so many issues at a given time. My own focus draws heavily on influence of an individual’s ascribed (social) identity on their relations with others, and the influence of medical practice and research on each of these. Language certainly mediates, but to examine this in the depth it requires would be to take away from my explication of the complicated relationship between self-identity, knowledge production and social relationships.

In certain significant ways, this view of intersubjectivity would break from the model of communicative action proposed by Habermas. For Habermas, identity is secured through intersubjective recognition. I follow Amy Allen here in her assertion that Habermas conflates different senses of “reciprocity” within his dialogical (“I-Thou”) view. Allen writes that Habermas views reciprocity as both involving mutual recognition and respect as well as the thinner notion of it as the taking up of the perspective of another, which happens in nearly all social interactions. The latter is a component of authority-governed relationships such as that of the parent-child relationship; here, one person controls the other’s contribution to the interaction. As Judith Butler identifies, the authoritative relationship is part of identity formation. By equivocating on the sense of “reciprocity,” Habermas obscures how communicative action is rooted in asymmetrical relationships of power. See Allen 2008, especially Chapter six.

Additionally, the dialogical model has important implications for responsibility. It takes a particular self, one with more than just spatio-temporal continuity, to make promises, create obligations, and be concerned for its future prospects; namely, to be responsible. Because the agent that operates within post-Enlightenment thought is impartial, objective and generic, and imputes a view of objectivity that promises transcendence, it “loses track of its meditations just where someone might be hold responsible for something…” (Haraway 1988, 579). A dialogical model of agency—moral, political and epistemic—might in fact offer better access to responsibility and accountability than is given by liberal philosophy.

Chapter Three

I credit Denielle Elliott with pointing out the division of labour within the epidemiological study of HIV/AIDS in Vancouver’s downtown eastside (personal conversation).

I note that there are a number of exceptions to this, primarily stemming from a small but important body of qualitative literature concerning HIV infection and treatment in the community. See for example, Elliot 2007; Robertson 2007; Patton and Loshny 2008; Culhane 2003.
3 More so for women who are younger and who smoke crack cocaine. As an epidemiologist once described it to me, the presumption concerning sex work also relates to the relationship between demographic categories used on surveys and labeling. This individual pointed out that someone might identify themselves as having participated in sex work once in the last six months on a survey (or to a physician or nurse in hospital), to be then classified as “FSW” in subsequent iterations of the survey and in studies that utilize longitudinal cohort data (as well as medical charts).

4 Refer to Nestler 2004 for a review of molecular and cellular mechanism of opiate and cocaine dependency.

5 Robertson and Culhane employ this term to describe the complicated realities within which women live, in the downtown eastside (Robertson and Culhane 2005, 9).

6 Specifically, neighbourhoods are associated with general (respective) patterns regarding routes of HIV transmission—Vancouver’s west end as the “MSM” epidemic, via sexual contact; the downtown eastside as an IDU epidemic, via intravenous injection. Clinically oriented studies also contrast injection drug users’ physiological reaction to ART with those of non-injection drug users, suggesting that were it only for perfect adherence to therapy, injection drug users (who now represent everyone in the neighbourhood) would have undetectable viral loads—another way that the categorization is naturalized as a “kind.”

7 While the studies discussed often generate laudable goals for health care provision, the movement back and forth between the IDU cohort and the overall neighbourhood point to the conflation of IDU practices with geographical residence, an issue that many individuals who reside in the neighbourhood berate as stigmatizing. Interestingly, the authors state that they don’t believe socially desirable responses to be an issue, since they were comparing non-DTES IDU with DTES IDU, assuming that it would only be injection drug use itself, and not neighbourhood residency, that would be potentially stigmatizing.

8 I note that Haslanger asks this question not because she is particularly concerned about the lack of the body in Hacking’s work, but because she is interested in semantic externalism, and the revolutionary (and debunking) power of critiquing the problematic implications or presuppositions regarding a particular grouping or class. Nevertheless, her point is apt for my purposes as well.

9 It is possible that this orientation to community-level data has historical roots in post-World War II-era social sciences. Kemple and Huey describe the study of “skid rows” (geographic areas of on-going neglect and disenfranchisement) in this era as treating the spaces (by the general public and by social scientists) as the inevitable consequences of individual pathology and, sometimes, personal tragedy.

10 I am borrowing this depiction of epistemology as it exists in affluent Western societies from Lorraine Code, who describes this epistemological stance as part of the legacy of the Enlightenment. See Code 2006.

11 Ignoring intersubjective aspects of data may likewise influence the ways in which a phenomenon is represented. In the example of illness understood as moral failure, it may be possible to conceptualize the meaning of “failure” in subjective terms (e.g. as the experience of “stigma”). But for as much as there is an implicit recognition of the role of the social (as in norms, standards, and what constitutes deviation from those) with something like the term “stigma,” the mobilization of such concepts within brute level data treats such issues as a psychological or personalized phenomenon to be overcome by the individual. This is most evident with the emphasis on constructs such as self-esteem and self-acceptance, or when the converse emotion, shame, is mobilized. Representing stigma in terms of the stigmatized individual’s subjective assessment of the impact of the stigmatizing condition on their efficacy in achieving ends or
goals fails to appreciate how stigma is an intersubjective experience. What counts as a particular stigmata and how it is manifested and embodied as the enactment of particular norms are particular to the historical conditions and cultural practices from which stigmatization develops.

The motivation for the analysis I offer comes in part from a desire to put the material and the historical back into the social determinants of health, while emphasizing their decidedly social nature. Predominantly, public health has turned its attention to the psycho-social determinants of health, a turn that can be construed as reflecting a wider neoliberal orientation, which I take to be problematic. On this issue, see Raphael 2006.

For more detail concerning the particulars of my research methodology, see appendix one. I have moved this discussion to an appendix because it is my contention that the analysis and writing of the project is a part of the qualitative method itself—knowledge production based on interpretive analysis of qualitative data is an iterative process, not a recipe. Trying to provide a rough and ready description of how many interviews were done and what coding method was used in which circumstances does not do justice to the approach that I have taken to the construction of data and my understanding of knowledge production.

I have chosen not to provide a more formal discussion of sampling methods and processes of data collection here because it is my contention that this type of discussion is reflective of a desire to fit qualitative research into an objectivist framework. Giving a “tool kit” view of methodology implies in some ways that any other researcher could follow these same methods and find themselves with a similar data set and similar analysis—this view flies in the face of how I have described intersubjective, interpretive research processes that critically depend on particular relationships, in particular times and spaces. Instead, what I have tried to offer is enough detail in my writing, that the methods by which the arguments I present have been constructed, and a level of self-consciousness about the process that engenders accountability in the research process.


Epidemiology, as the authors of the British Medical Journal text on the subject write, ought to follow the adage, manus sordidae, mens pura: dirty hands, clean mind. See “Information Bias,” BMJ Epidemiology Hypertext, Epidemiology for the Uninitiated (http://www.bmj.com/epidem/epid.4.html#pgfId=1002291). It’s worth noting that the purity of the mind is contrasted here with the “contaminating” body—reinforcing various elements of the objective/subjective binary and the Cartesian dualism that underpins it. The adage also implies that through the function of the mind, “messy” data, contaminated by bias, can be purified and sanitized to a form that allows it to stand on its own, separate from the actions of the minds that cleaned it up. I examine this issue in further detail in chapter three.

Admittedly, I have characterized the practices of social epidemiology as being strongly reductionist and positivist. Although I have supported this characterization with content analysis of a number of studies, I will also attempt to give a brief defense my stylized version of social epidemiology in more general terms. Marcia Inhorn provides a nice counter-argument to my characterization, writing, “epidemiology is not a monolithic enterprise, and not all epidemiologists are “reductionists,” narrowly focused on limited conceptions of diseases, risk factors, and their numerical interplay. Epidemiology is neither lacking in breadth, interdisciplinary vigor, and critical reflexivity, nor narrowly focused on limited notions of disease, risk and causation” (Inhorn, 1995). While all of this may be true, Inhorn’s comments do not undercut the issues I have raised. The reflexivity Inhorn cites is limited to the focus on observer bias and
not the location of the observer/knower in the interpretive process; even when examining wider
“environmental” factors associated with correlates of health, the methodology remains such that units of
analysis are constructed as interchangeable; considerations of the relationality of data are limited to those
that are contained within the field of study, and exclude the observer/knower; finally, the authority of the
claims put forth (particularly if the findings are tied to politicized processes and events) hinge on the
“objectivity,” rather than constructedness of the results.

One might critique ethnographic works for their focusing on individuals and processes that are far
removed from social “norms,” but this is a critique of the tendency to exoticize the object of study, not a
critique that the study somehow fails to capture important social phenomena. The latter idea rests on the
fallacious assumption that “important” social phenomena are those at the mean. It is this assumption that
drives the move to offer generalizations based on “representative” data.

This orientation informed my research practice, for instance, insofar as I attempted as much as possible
to review interpretations and findings from field data with numerous participants, often revising and
reformulating ideas in light of their responses.

Cerwonka makes this point very well when she draws on David Weberman’s work, citing him as
follows: “The object is underdetermined because it is not self-contained, it is not self-contained because it
is partly constituted by its relational properties, and its relational properties vary according to the temporal
(and perhaps cultural) position of the historically situated knower” (Weberman, 2003; quoted in
Cerwonka, p. 31). Whether collaborative or not, the organization of embodied experience and its
inscription in text is relational, obliging the “vicissitudes of translation,” to quote Clifford. This is a
challenge to any kind of behaviouralist research paradigm, given the focus of behaviourism on causally
efficacious individual actions and motivational states as explanations for “macro” social phenomena.

Malkki and Cerwonka describe this process of interpreting and writing fieldwork as spiral, rather than
linear (Malkki 2007, 166).

This was not a straightforward or unproblematic position to be in, as the wealth of literature critiquing
“activist ethnography” attests to.

Carly would sometimes announce to people who were dealing on the street, “she’s not a cop!” or say
that I was a medical student and joke loudly with me, “I can’t believe people think you’re an undercover.”
Steven Vanderstaay gives a nice discussion of the significance of representing research relationships in
such ways, saying that having such arrangement not only have an explanatory function, but that they can
also help to bridge social, economic and cultural differences. See Vanderstaay, “One Hundred Dollars and
a Dead Man,” p. 379.

Chapter Four

“Cleaning” data is a term used by some researchers to depict the process of preparing data prior to
analysis. It entails double checking the coding system used on the data and resolving inconsistencies and
discrepancies. It also includes ensuring that larger amounts of text are broken down into smaller
categories (preferably binary numeric categories) that are meaningful for statistical analysis. The
interesting thing, from my perspective, has been to see the way in which inconsistencies in data are
resolved. If a research participant responds to a question by saying “a few” (e.g. how many times a day
do you inject heroin – “a few”), different individuals carrying out data entry might have a different
understanding of how to represent “a few” numerically, leading to disagreement in the number entered in
the data field. Likewise, there are inconsistencies in the interpretation of what someone might have meant
when referring to social support programs used, particularly if the name of the social support is not commonly known amongst the researchers entering data, and the individual who carried out the survey questionnaire is not available to respond, or does not remember that particular survey. It may also involve removing variables that are not thought to relate to analysis.

2 The linkages between drug use and depictions of mental illness are numerous and varied. Imagistically, one might think of the cult film “reefer madness,” with the realization that it was produced not as satire, but in earnest. Such linkages are not just in the popular imagination. Along with the fact that substance abuse is itself considered a DSM-IV disorder, there is increasing discussion of addiction as a chronic relapsing mental illness. Amongst the urban poor, both drug use and mental illness are seen as rampant—poverty being the inevitable outcome of these conditions (see Culhane 2003 for a compelling discussion of this reversal between cause and effect). Similarly, it is increasingly common to refer to drug users in terms of “dual diagnosis,” the description given to co-occurring substance use disorder and mental illness.

3 For a good discussion of the use of the term “stability” in addictions and substitution therapy discourses, see Fraser and Valentine 2008. The authors describe that there are commonly two subject-positions available to methadone maintenance therapy (MMT) clients: the chaotic addict versus the stable consumer. That said, their own research demonstrated a greater variety of identities available to MMT patients, including the “dissatisfied customer,” a subject-position that is tied to the habitual nature of MMT and being made to queue, face hostility from staff, as well as impersonal and distance service. Similarly, “stability” had a different connotation in the discourses they had studied. Rather than relating to being “clean” (abstinent), the continuum between heroin and methadone meant that MMT clients were still, in many ways, considered addicts. They were “stable,” though, when they were compliant with treatment agreements, held down jobs or housing, stayed away from crime, avoided jail, were well-behaved at the clinic, etc. Stability has a wide range of behaviours and social situations it might refer to, though it is held as oppositional to “chaotic,” even though the two terms may refer to completely different criteria, and the distinction between the two often problematic (Fraser and Valentine 2008, 118-133).

4 The 2005 Methadone Maintenance Guidelines for the College of Physicians and Surgeons of Ontario, widely adopted across Canada, defines clinically stable patients as those who demonstrate the social, cognitive and emotional stability necessary to assume responsibility for the care and safeguarding of methadone, and use it only as prescribed (Methadone Maintenance Guidelines 2005, 31). This entails (1) the elimination of “problematic drug use;” (2) a stable methadone dose and an emotionally stable patient; (3) stable housing, employment and social supports; (4) adherence to methadone program guidelines (ibid).

5 See Elliott 2007; see also “Debating Directly Observed Therapy (DOT) and ARV Adherence Among the Urban Poor.” Abstract WEAD0304, presented at AIDS 2008, Mexico City.

6 Helen Keane’s work on recovery discusses ways in which the self-help literature’s emphasis on addiction-free self-formation through daily habits and practices conflicts with its promises of a more transcendental form of freedom and autonomous agency. See Keane 2000. Fraser and Valentine,
discussing methadone maintenance therapy (MMT) and the ascribed characteristics of MMT clients, argue that some of the rhetorics of drug treatment offer two possible subject-positions: the chaotic addict or the subdued methadone user. They note that neither of these conventional categories makes room for an understanding of agency. They contrast their own research findings, and emphasize the notion of a dissatisfied customer, in order to highlight the ways in which commercial aspects of medicine are part of addiction services in their setting, and how individuals using MMT occupy simultaneous patient/client positions. See Fraser and Valentine 2008.

7 See, for example, The BC Centre for Excellence in HIV/AIDS (BC CfE) “Antiretroviral Update,” which includes BC guidelines for treatment as well as a comparison between international guidelines and those suggested by the BC CfE.

8 In a parallel fashion, it is often the case that when patients who are seen as likely to have difficulty with non-adherence are going to begin ART, they are started with a two-week “trial” of vitamins, to see how they are going to do, whether they are able to take the vitamin each day, either at the pharmacy, at a directly observed therapy (DOT) program site, or via pharmacy bubble packaging, which is then examined by a nurse or physician to determine the level of adherence. “Engagement,” just as much as “non-engagement” regarding other forms of medical treatments, is taken to have implications for antiretroviral therapy, which is why I have extended my own analysis to include an interpretation of the conditions under which these diverse actions occur.

9 Interestingly, though, research practices do implicitly reproduce a version of adherence to ART that depends on abiding by wider guidelines generated by expert bodies concerned with not only the appropriate combinations of antiretroviral medications, but other clinical actions such as the timing of blood work, anal and cervical PAP smears, and vaccinations. This version of adherence though typically relates to health care provider adherence to HIV treatment guidelines, and not to patient health behaviour. Health care provider adherence to guidelines is taken to be entirely distinct from patient adherence to medications.

10 Not surprisingly, a substantial amount of effort is spent convincing the reader of such reports that drug users can, contrary to popular opinion, provide credible testimony regarding their adherence.

11 Of course, there is some overlap between the hospital and the community clinic, inasmuch as discharge summaries and case conferences about behaviour on the ward do sometimes make their way to clinical staff in the community. But for the most part, leaving AMA or being on the balcony are not indicators that are heavily relied upon within the clinic. Different proxy measures, also often related to assessment of frequency of drug use, are employed instead; these do not necessarily overlap with the proxies employed within adherence research.

12 Peter Conrad similarly describes this phenomenon, with respect to patients following treatment programs for epilepsy. Conrad writes, “Although many people failed to conform to their prescribed medication regimen, they did not define this conduct primarily as noncompliance with doctors’ orders.” Conrad conceptualizes this as indicative of “medication practices,” in which the prescribed orders are one part of a medication practice—self-regulation of medication may then be understood in line with the patient’s perspective. See Conrad, 1985.

13 As I shall discuss further on in the chapter, there was also somewhat less reliance on the use of categorizations and ideal-types in such clinical spaces, given that they tended to have a more complete view of their patients as people living within a particular environment, with a given life history, rather than as instances of an ill-conceived social identity.
Other women similarly described the pleasure of drug use as being not only pleasant in itself (though it was that, at times), but also pleasurable in letting them step outside of the problems, the illnesses, the pain they experienced as part of their everyday life. Carly once took me to a section of a public Chinese garden where she used to come to after she’d gotten high, to sit in between the bamboo and “get away from the riff raff.” Illness, suffering, and pain are also entwined with street life in the neighbourhood, and difficult to escape when one has little or no money and the need to be near the health and social services that order the lives of individuals in the community. As I will explore in later chapter, substantial problems arise when drug use is seen as a lifestyle choice that is incompatible with “choosing” to follow through with health care services. I will contend that there is a need to understand the significance of drug use, and make using less incommensurable with health care services, if people are to have any substantive quality of life.

While I hesitate to engage in any kind of romanticizing of what life is like when one has informal, illicit economies and substance use to contend with on a daily basis, it is disingenuous to ignore this aspect of women’s experiences, as they describe it. In addition, to ignore women’s perspectives on their ability to hustle would also mean ignoring the views of the health care workers who see them on a regular basis, many of whom would trade stories about their entrepreneurial skill as dealers and workers.

Although this imagery has shifted somewhat with the advent of HAART and the declaration that HIV is now a “chronic” disease (as least in countries of relative wealth), even the chronic disease model invokes notions of control and management of symptoms, opportunistic infections, and side effects. For women in the community though, the concept of HIV as a “manageable” chronic disease, one that can be so well controlled by medications that one returns to a state of relative good health is, for all intents and purposes a fiction. The relentlessness of contending with HIV care, the immanence of serious illness and death within the community, and the relationship between a marginal existence due to drug use and that of existing on the margins of life due to HIV/AIDS all fly in the face of the chronic disease model.

Helen Keane describes the tendency for earlier texts of methadone maintenance therapy (MMT) that engage with Foucauldian scholarship to emphasize the disciplinary aspects of MMT, interpreting it as part of the production of docile bodies. Recent work (e.g. Fraser and Valentine 2008) emphasizes more complex understandings of power within MMT, exploring the effects of regulations and practices, and the significant impacts of these on experiences of treatment and social identities. In Fraser and Valentine’s work on MMT (which Keane discusses in some detail), the authors examine how MMT is a spatial-temporal product co-produced between regulators, physicians and patients/clients. In this sort of analysis, we see locally specified versions the two “dreams” of clinical medicine: discipline and strict medicalization, as well as the eradication of disease through the organization and supervision of the environment, and uptake up its norms and ideals. See Foucault 1973/1989, 36-37; Fraser and Valentine 2008; Keane 2008, 450-452.

Denielle Elliott makes a similar remark about physicians and researchers working in the downtown eastside. Elliott draws a contrast between the depiction of patients’ lives as “chaotic” while the irregular schedules, frequent conference and medical travel often see researchers and physicians in an unpredictable life/work pattern. See Elliott 2007.

Even as substance abuse treatment services are generally thought to optimize antiretroviral adherence amongst drug users, the association between treatment for substance abuse and HIV treatment has also been reported to be limited to current receipt of medications and not actually extend to longitudinal adherence to medications (Palepu et al., 2004). We might reasonably ask why, given these discrepancies between methadone and adherence, linking methadone to ART is nonetheless considered best practice for those with opiate dependence. There are suggestions that methadone serves a disciplining function for
patients within the health care system (Bourgois 2000; Pedersen 2002). While this viewpoint is in many ways compelling, my own experience has led me to wonder whether it represents methadone practices as too unified, and the power of the medical system to control individual bodies as overly disciplinary. There is something interesting about the fact that many patients I had followed did actively seek to be on methadone at certain times, finding it helpful. At other times, those same individuals saw it to be controlling and problematic. The productive aspects of medicine are intertwined with its disciplinary and controlling elements, and so I hesitate to suggest that we can think of something like substitution therapy in one or the other terms.

20 Explanation of salvage therapy…Ritonivir is an antiretroviral drug that is used as a “booster,” a drug which increases the efficacy of other antiretrovirals, but is not effective as on its own. As drug regimens become more complicated, combinations of drugs are no longer available in a single tablet or capsule, leading to a very large number of pills that are required to be taken a number of times in a day.

21 In their work on the use of methadone substitution in opiate dependence, Valentine and Fraser discuss the metaphor “liquid handcuffs,” a description commonly touted by both patients/clients and prescribers. It vividly emphasizes the view of methadone as a form of incarceration and way to control the behaviour of those who are opiate dependent, while also references the issue of criminality—heroin being illicit while methadone is not (Fraser and Valentine 2008, 48).

22 Deborah Lupton makes this point when examining the influence of Foucauldian scholarship on sociological notions of medicalization. Rather than simply taking medicalization to be an oppressive force generated by medical institutions, controlling lay experience and denying independent human action, Foucault provide the tools to understand the positive and productive elements of power relationships, and the ways in which individuals themselves take up and enact “expert” knowledge (Lupton 1997, 104). What is also of interest are the ways in which individuals may resist and subvert medical authority, by being non-adherent, for example. And, as Lupton rightly points out, may occupy both the compliant and non-compliant positions simultaneously or variously (ibid, 105).

23 Physicians and nurses may inadvertently reinforce this general view when they describe to each other how “refreshing” it is to not have bolded (i.e. abnormal) blood panel results, or to have “good news” to report to patients instead of the usual (and expected) “bad” news.

24 Missy described this concern to me one day when she reflected on whether or not she might get in touch with her family again, saying, “I haven’t seen my mother in 10 years and I just have this vision, the next time she’s going to see me, I’m going to be in a casket. I used to call my mom every other day we’d talk, now I haven’t spoken to her in 10 years, just took off, haven’t talked to her since. Now I’ve got to tell her that I’ve got HIV and cancer?” The rhetorical tone of her question punctuated the sense that it was a worry about being seen by her family as a failure that was her concern.

25 The final month of Carly’s life similarly traced out this dynamic—Carly had been in hospital with complications from Hepatitis C, and had left one hospital, only to show up at a different hospital a few days later. Eventually, when she was re-admitted through the emergency department of the first hospital, she was asked rather unceremoniously, what did she expect them to do for her, after all the back-and-forth between hospitals? She was dying, after all. Upset at being told this, she left again, this time back to her partner’s room in the downtown eastside, where he attempted to help her while she moved in and out of consciousness, and her body continuing to swell from ascites due to a failing liver.

The community clinic staff quickly came to their shared room in the supported housing unit, bathing her and helping her frazzled partner figure out what to do for her. In the end, she went back to hospital via
ambulance, and spent another month there, her levels of consciousness varying over time. One physician said to me that they would keep doing investigations to see if there was anything for her, but that it would be essentially useless, if she was just going “take off” again, when she was able to. The differences between the approach of the community staff and those in hospital were tremendous, in many ways. Carly’s reputation and the past challenges that the community health providers had with her meant little to them when they were trying to figure out how to best make her comfortable and ease the transition to palliative care. Such health care providers also had a view of her longer medical as well as life history. In hospital, however, the aspects of her reputation that were specifically related to non-adherence were brought forward again and again. To be fair, hospital staff had to make decisions concerning whether to treat aggressively or palliate, but what matters to my point is first, that her rejection of care at the second admission was in relation to what she perceived to be harsh treatment and being overwhelmed by a terminal prognosis; and second, that her reputation followed her, even to her last days, when she was in clinical space that has a tendency to rely on types and kinds, more so than when her care was being coordinated by those who knew her in the community.

I note that it is quite common in clinics and hospital, to develop “behavioural contracts” with patients who are deemed to be difficult (e.g. being verbally abusive to staff; leaving hospital to buy alcohol and returning intoxicated). This is decidedly not the same as building consensus—it is formalized discipline.

There are, of course, other depictions associated with both drug users and the downtown eastside community that Rampant mental illness is also part of the imagery surrounding drug users, particularly those who are homeless or spending much of their time on the street (think of the homeless “pigeon lady,” or the raving man on the street corner preaching the end of the world; drug use “frying” the brain). Finally, the image of overwhelming victimization and personality disorder related to trauma is another image that is applied to women in the community.

My description of how “drug user,” as a social identity representing a kind of person, is a category that has a low level of what Fricker refers to as “identity power,” the operation of social power that depends on conceptions that are informed by a collective social imagination concerning a particular social identity. Even for those who are unaware that they are employing identity power in either asserting or denying particular claims, or perhaps do so in a benevolent or paternalistic way, identity power is still at work. See Fricker 2007, 14-15.

I have borrowed this phrase from Merrill et al. 2002.

As intellectual labour, it is both obvious and overlooked within the Western individualist paradigm that research has to be generated by the activities, interactions, and investments of time and energy of numerous individuals, particularly that of the researcher. It is therefore disingenuous to imply that subjective responses and personal investments don’t take place within all forms of research practices. But more to the point, situating oneself as a researcher is as much a concern for the ethical aspects of research as it is the epistemic ones.

Fraser and Valentine likewise describe the control of space within methadone clinics, which is interconnected with the control of temporal qualities of MMT. Many of the space-time configurations are organized around security and public order concerns; the clinic implicitly references the prison. Physical aspects of the locations might reinforce distance between patients/clients and health care providers; and as in correctional facilities, they may also ignore issues of privacy (e.g., queuing outside the premises, providing urine or blood samples with few barriers to the view of others in the clinic, etc.). But as the authors point out, patients/clients intra-act with the temporal and spatial qualities, such that particular
kinds of people are produced through the practices. This is a co-production, not simply a disciplining of a decline body. See Fraser and Valentine 2008, 103-112.

32 Here it is crucial to emphasize how offering a smooth explanation of the seeming inconsistencies depends on the processing and constructing of the events by different knowers. It is through dialogical epistemological practices and through locatable knowers that these claims, and those who make them, can be called to account (Haraway 1988, 583). Hence, my interest in the partial perspectives offered by both researchers and research participants, as important contributors to the production of knowledge as well as the ethos of research practices.

33 I have taken this point from Walter Lippmann, “Stereotypes.” See Lippmann 1962.

**Chapter Five**

1 By dividing my discussion between rational actor models and the self-as-rational agent, I run the risk of making the tacit suggestion that these are two distinct objects of thought. From my discussion of liberal humanism in chapter two, I hope that it is clear how interrelated these are. The division, between chapters four and five is not metaphysically deep; it relates to the structure of my argument in relation to my empirical study. Namely, the rational actor model is overlaid by behaviouralist approaches to research in biomedicine. In order to see how this model shapes lived experience within the medical system, a more detailed discussion of agents and identity is needed—hence the emphasis on the self-as-rational agent. This latter object of thought connects back to the methods of study by way of my kind-making (looping effects) argument. Both objects of thought are, as argued in chapter two, embedded within the tradition of liberal humanism.

2 I have taken the particular formulation of these questions from Lorraine Code’s *Ecological Thinking*. See Code 2006.

3 On an interesting linguistic note, “adherence” was introduced into the medical lexicon after it was argued that “compliance” (defined as the extent of correspondence between the patient’s actual dosing history and the prescribed regimen) invoked value judgments and blame, while adherence suggested more of a partnership between patients and prescribers, making cognitive room for provider behaviours, social, environmental and regimen factors in discrepancies between medication prescriptions and patient’s actual dosing (Chesney 2000; DiMatteo 2004).


5 Lorraine Code explores the images of scientific activity through what she refers to as the “Scientific Imaginary,” that is, the figurations of scientific activities as objective, certain, and its practitioners as holders as epistemic authority. The scientific imaginary that Code examines is one of mastery and instrumentality; of a limitless sense of the ability to predict, manipulate and control what exists within the domain of “nature” (p.25-36; p. 245) Scientific enterprise also construes itself as outside the structures of privilege and power (p. 244), even though the operative imagery of science is simultaneously understood to be practiced by privileged, mainly white, men (p. 246); as in [1].

6 Denielle Elliott likewise discusses the use of the term “chaotic” to depict residents of the downtown eastside community, particularly its use as justification for structured medication interventions such as directly observed therapy (DOT) programs. Elliott convincingly argues that chaos versus stability relate to
the determination of whether a patient is able to meet the demands of the public health system, and partake in the maintenance of public order within the community. See Elliott 2007, 87-91.

7 “Euphoraphobia” is the same fear of euphoria as Klerman depicted when coining the term “pharmacological Calvinism.” See Klerman 1972. Both terms are references to the distrust of using exogenous agents to attain pleasure. See also Stephen Braun, *The Science of Happiness*.

8 I have borrowed this phrase from Diana Meyers in, “Decentralizing Autonomy: Five Faces of Selfhood.” See Meyers 2005, 43.

9 In fact, I was amazed by the number of schedules Carly had in her head—who worked which clinic on which day, when the clinic or the assistance office closed early during the week, which day she could get which food items or a hot meal, in which location.

10 See again Elliott 2007.

11 Missy *could* have been known as somebody who self-discharges, classified by health care staff as a “self-discharger,” which would have placed the actions and ostensible reasons for them within her perspective. But she wasn’t. In the entire time that I had worked in the inner city, it’s clinics, and the hospital, I heard the term “self-discharge” twice; once by an anthropologist who was preparing a research interview guide, and once by a community medicine physician who works primarily in research.

12 In various works, Susan Brison explores the role that others play in helping to reconstitute oneself through uptake of one’s narrative of trauma. Although this is an interesting and provocative view with respect to a relational account of the self, it is still the case that the memories are one’s own, even if it is the case that they are being interpreted and reconfigured with the participation of others. Scheman’s point, as I understand it, is a different one, that others’ memories of us play a role in the telling of a person’s life, such that some of those lives, filled with privileged memories from others, are smooth and blemish free, other lives are, rightly or wrongly, distorted and fractured by others’ memories. See Scheman 1997, 126.

13 “Frequent Flier” is the pejorative term colloquially used to describe individuals who regularly use the hospital services, particularly those from the inner city community who present themselves to emergency after a previous admission and self-discharge. They are often presumed to be “drug seeking,” rather than legitimately in need of health care services. The name parallels what hospital staff refer to as the “revolving door” phenomenon. Much like the references to Federal Prison as “club Fed,” the frequent flier term depicts middle class business or vacation travel, implying that the individuals who referred to in this way are somehow getting away with something, milking the system or are not being subject to adequate punitive measures for their illicit behaviour. The name “frequent flier” fails to address (a) how very ill many people who live on the street are and (b) how difficult it can be to see a family physician or undertake preventive health measures while living in a hostel room with no kitchenette and no private bathroom, particularly when one’s survival depends on partaking in informal and illicit economies. Moreover, it fails to recognize that many individuals desperately do not want to go into hospital, and often only do so when they are too sick to refuse.

14 Cindy Patton and Helen Loshney give a nice description of this in their analysis of home care services within the downtown eastside community. See Patton and Loshney 2008.

15 “Fast hands” refer to someone who is able to move drugs or stolen/pick-pocketed goods quickly and undetected by those around them.
16 See Whynot, Elizabeth, 1997. Similarly, Marshall et al. (2008), “Physical Violence Among a Prospective Cohort of Injection Drug Users: A Gender Focused Approach,” explicitly cite impairments in mental and emotional health resulting from violent encounters, including depression, anxiety, mood disorders, PTSD, suicidal ideation, and substance disorders. In the next sentence the authors state that violence (e.g. physical assault by intimate partner) has been linked to increased HIV risk behaviours, including unprotected anal intercourse, participation in sex work and syringe sharing, making an implicit link between violence, “risky lifestyles,” and mental/emotional capacity. The study demonstrates an association between mental illness and received violence for both males and females, but the cross sectional analysis cannot provide directionality for these experiences. Based on the study findings, the authors suggest that individuals ought to be able to use drugs where they can be monitored by health care providers so as to protect them from the police and predators who cause violence, constructing a victim subjectivity as well as justifying a protectionist/paternalistic solution.

17 When selecting field notes for the chapter, my surprise led to a stronger concern, that by including this particular statement in the excerpt, I would be inadvertently colluding with the all too common denial of the existence of racism in Canada. They were, however, her words, and it was important to both of us that she be able to express herself as she saw fit.

18 I thank Treena Orchard for pointing this contrast out to me.

19 A proponent of this view might argue, therefore, that theories of health behaviour that employ a rational actor model are useful for certain purposes that are distinct from my own. Perhaps health behaviour theories are interested in explanations that operate at a different level than that of personal experience—it is would be mistaken, in that case, to critique such theories on the grounds that they fail to adequately capture such experiences. That the theories miss personal experience is merely a benign consequence of an otherwise useful model of rational actors.

20 I gratefully acknowledge Scott Anderson for raising this issue and clarifying the scope of this objection to my position. This objection is based upon the work of Judith Shklar’s, “The Liberalism of Fear.”

21 Many theorists approach the concept of identity and the repression of difference through the work of Jacques Derrida, who identifies the oppositional and repressive logic as being part of all western metaphysics. Pairs of terms sit in hierarchical opposition, which valorizes one term and ignores its reliance on its opposite; the resultant deconstructivist position aims to reject the language of identity. A different approach has been to follow Jacques Lacan, which view self-identity as repression, but accepts this as the price of participation in the social/symbolic order. For a discussion of these positions see Weir 1996, especially introduction as well as chapters one and six.

22 Specifically, the DSM IV diagnostic criteria for substance abuse requires that in the previous 12 months, an individual experiences a pattern of substance use which results in one of the following: (1) recurrent use resulting in a failure to fulfill obligations at work or at home; (2) recurrent use in situations which are physically hazardous (e.g., driving while intoxicated); (3) legal problems resulting from recurrent use; or (4) continued use despite social or interpersonal problems caused by the substance use. The symptoms do not meet the requirements for substance dependence (DSM-IV; my emphasis). The descriptions of the criteria for abuse depend to a great degree on social conventions and norms—what a person’s obligations at home or work are; legal problems, which depend on judicial conventions (e.g. trafficking and possession charges can only be legal “problems” in a social environment where trafficking and possession are criminal acts); specifically, what count as social or interpersonal problems.
Feminist theorists have also highlighted this issue in their discussions of the influence of norms of femininity on women who recognize the norms as problematic and negate their validity. Even where such norms are not mystified, fragmentation may be experienced due to the simultaneous rejection and influence of pervasive socially ascribed roles and identity traits.

There is certainly more to consider with respect to the notion of repressive or exclusionary theories of self-identity—whether, for instance, it is possible to conceive of identity in a non-repressive way. This is well-trodden ground within psychoanalytic feminist thought, and what little attention I might give to the question will not substantially further the debate. At this time, allow me simply to gesture toward a number of philosophers whose work suggests that by reconstructing the self to include embodiedness, heterogeneity, difference, particularities and a dialogical model of connection rather than a monological model of mastery, universals, transcendence, and unification. A new accounting might make it possible to conceive of self-identity and individuation outside of the exclusionary model. See Alison Weir 1996; Margrit Shildrick 1997; Lorraine Code 2006.

To understand this claim, consider Jacqueline Rose’s argument, that self-identity, in one sense, is like language—it is part of the subject’s capacity for social participation. This form of self-identity requires some level of psychic integration. The image of a non-adherent patient as chaotic implies a lack of integration of the self—one is unable to hold oneself together. The lack of coherence excludes such an individual from social participation and, as Allison Weir points out, it is not surprising that coherence of the self is a precondition of any commitment to maintaining an ethical or political position. Even if we agree with this line of thinking, that a lack of integration akin to psychosis denies the possibility of social participation, it is worth emphasizing that the depictions of non-adherent patients as chaotic is often hyperbolized and unwarranted. Their exclusion is maintained on the basis of their failing to meet the standards of rational selfhood, but this is not descriptive or “natural.”

Fricker, along with other feminist epistemologists, point to the way in which the foundations of science and medicine are steeped in this exclusionary granting of epistemic authority—good informants are like 17th century scientists—perceptual competence depends on one’s status as a gentleman/property owner in good standing. See Fricker 1998, 170-171; Shapin 1988)

It’s not the case, of course, that all home care nurses approach their work with the attitude that they are entering a private, normally non-medical space when they carrying out their home care duties. Some nurses described their colleagues as seeing their work in terms of moving the clinic location temporarily to the home, until their patients were back on their feet (and able to go to the clinic) or for palliative patients, until the end of their lives. My point is only that it is much more likely that the space functions in a different way when compared to, say, a hospital setting, in which there are no rhetorical or imagistic cues to suggest that the space be treated as anything other than the domain of the health care professional.

Chapter Six

I want to be clear in circumscribing my arguments here: my analysis has not been meant to claim a direct cause-effect relationship between holding certain social identities as deviating from the liberal standard of reference and non-adherence to ART. I have chosen to use the term “milieu,” which Lorraine Code argues for in Ecological Thinking. Following Patrick Hayden’s analysis of Deleuze, Code suggests that a milieu gets away from the traditional dichotomy between subject (humanity) and object (nature), a dichotomy that is required for causal/predictive analyses (see Code 2006, especially chapter one). The emphasis is instead on the interrelationships between living things and their environments, which encompasses multiple dimensions of interactions, at varying levels. The connections made are among “the physical, biological and chemical and the social, ethical and political” (Deleuze and Guattari, cited in
This sort of analysis emphasizes interconnections and possibilities, rather than causes and predictions.

Important, my purpose is not to suggest that all patients’ requests are always reasonable or that they ought to be met at all times—it is to demonstrate how interpersonal as well as institutional dynamics within clinical settings can lead to withdrawal from the health care field.

I thank Scott Anderson for helping to clarify the application of Wardlow’s concept to the situation I am describing.

With respect to the technical issues discussed in the field note selection, it is widely accepted that although patients are encouraged to begin antiretroviral therapy before their CD4 cell count is below 250 (a cut-off given based on the observation that AIDS-defining conditions generally begin to afflict individuals once their CD4 <200), a count of 260 is adequate and initiating therapy isn’t an immediate necessity. Different classes of antiretrovirals are thought to be more susceptible to resistance mutations in the viral population than others; resistance is understood to develop through selective pressure on the viral population, when medication levels are not high enough to suppress viral replication (i.e. the patient has not been adherent to the regimen). In the NNRTI class, drug resistance mutations accumulate more rapidly than in another class, for example, the protease inhibitors. Once resistance mutations accumulate within a class, it is unlikely that a patient will be able to use any other medications of that same class.

This may seem somewhat paradoxical—nurses, are by definition, “medical” personnel. Having a nurse assist you with booking appointments, ordering a taxi cab to bring you to that appointment or provide a ride, even assist with looking for housing or a food security program, seems as though it would increase the presence of the medical system within one’s day to day life. It is even more interesting, then, that for some of the relationships between the home care nurses and their patients, the qualitative aspects of the relationship negated this obvious way in which the health care system was an intimate part of their lives. This wasn’t always the case, as my earlier discussion of Angel and Pearl pointed out. But where it was, the nurses were very careful to ensure that what took place within the private spaces of their patients’ lives was under the direction or control of the patients themselves, and what they were willing and able to assist with did not begin and end with the aims of the nursing case management agenda.

Consider the contrast case, a traditional liberal view which says that one expresses one’s will when one acts. There is a tacit assumption of a compliant social structure within which one’s choices will be carried forward to action, if it is simply accepted that choices require reasons for action, and reasons are representative of a unitary self. For a single you to be expressed through choice (i.e. reason), it has to be the case that one is not faced with incommensurable and equally necessary courses of action.

To illustrate this point: attempts to dismantle social welfare programs in both the United States and Canada have often invoked the notion that such programs encourage dependency on the governments and undermine individual autonomy. There is a presumption that social goods are equally able to be accessed within society, and that the need for social assistance reflects poor decision-making and a lack of desire to be self-reliant. Faced with greater restrictions on accessing benefits (e.g., mandatory “workfare” programs that leave little way for single parents to care for young children and receive benefits), an individual might then be put in the position of “choosing” illicit ways in which to acquire additional income, which allow them to care for children during the day, or perhaps “choose” dangerous work in order to be paid a higher amount. Moreover, as Lorraine Code argues, social welfare programs also maintain an implicit distinction between social insurance (e.g., employment insurance) and public assistance (i.e., welfare) and suppose that individuals who do not receive social assistance benefits somehow make their way in the world on their own, even though their own successes are the result of
structurally invisible social supports. A failure to see how such structures disadvantage some but improve the circumstances of others perpetuates systems of privilege and power. See Code 2006, 180-185.

8 This particular phrasing comes from a presentation given by Stacy Leigh Pigg, entitled “Globalizing the Facts of Life.” Pigg argued that the idioms of rationality, as part of the sexual education/sexual health content of HIV/AIDS prevention programs in Nepal, function to demarcate social positions of race or class superiority (The University of British Columbia, March 4, 2010).

9 “Poly-doctor” is a term used by health care providers to indicate that a patient is seeing more than one physician – the term’s pejorative connotation comes from its association to the psychiatric language of personality disorder (e.g. in borderline personality disorder, patients are discussed as seeing multiple members of health care teams and splitting them apart in order to manipulate the patient’s relationship with them), as well as with the addictions language of “poly-drug user,” which refers to an individual who uses multiple addictive substances, e.g. heroin as well as crack cocaine and amphetamines.

10 Although Lugones employs the notion of differing social worlds, through which a bicultural person travels, I want to make clear that neither of the instances of differing spaces are meant to reinforce the common assumption that those living in the inner city community are somehow radically different from the generic norms of humanity, so as to be an alien species. This amounts to a form of soft culturalism, which has the tendency to reinforce negative evaluations of group members, naturalizing difference and furthering exclusion. Thus, I have opted to use the term “spaces” rather than “worlds.”

11 See, for instance, work by the BC Centre for Excellence in HIV/AIDS detailing the financial cost savings of treatment for all HIV-infected people in the community; Dr. Julio Montaner has suggested in numerous public discussions that, rightly or wrongly, the cost savings is a major motivation of the interest in funding the scale up of treatment in BC by the provincial government.

12 For Anglo-American philosophers of agency, this discussion might seem troublesome. Surely, to be a candidate for responsibility or rationality (which one might achieve or not), one must be within the set, “agents.” How is it that we can even conceive of depictions of certain social groups as being non-agentic selves? Part of this trouble is an issue of how agency is understood—whether it’s a kind of capacity that has substantive features or requirements, or whether it is a logical category (as in, one does an intentional action, therefore one is an agent, regardless of whether that action is deemed irrational or irresponsible). The difficulty is located in the tendency for conventional liberal accounts of agency to use autonomous agency as a reference standard—the ideal sets the terms of the discussion, which can ultimately collapse the distinction between agency as a logical category and agency as a substantive capacity. When I use the term “non-agent,” in reference to substance using individuals, I am highlighting how they are understood within the liberal frame of reference that holds as opposing the normative ideal. This is not to make any claim about agency as a logical category.

13 We might wonder whether this is unnecessarily pejorative and ultimately a privileging of the conventional view that agency is, in fact, rational and autonomous. We might also ask whether this depiction of agency isn’t hopelessly nihilistic. Why not just call it “agency”? Calling it “negative” does indicate that there are damaging elements to the actions—when the women I followed would leave hospital against medical advice, for example, they did suffer health consequences and were further maligned as irresponsible or irrational through these actions. As this last point indicates, it does reference the standard: rational autonomous agency. But by attaching “agency” to this destructive element, there is a way to refuse the cogency of the ideal, while implicating it in the construction of the actions.
I use the term in the same spirit as it was developed by Bartky. Specifically, her analysis of psychic alienation resulting from stereotyping and the internalization of an inferior position within society are of importance here. Two issues are of interest here: first, Bartky writes that stereotypes limit the extent to which those who hold such beliefs are able to understand the oppressed group member’s needs or respect their rights (likewise, their dignity). This is precisely the issue that I have been drawing attention to with my discussion of logistical challenges in the health care field and women’s withdrawing from care. Second, the internalization aspect points us to an understanding of how it is that oppressed persons often police themselves in such a way so as to reinforce the stereotypes and maintain their positions of disadvantage and lack of privilege. Alternatively, they may live a struggle against adopting and refuting the images and norms applied to them (Bartky 2005, 106-107).

To appreciate the relationship between negative agency and issues of oppositional social identities and the exclusion of difference, we might also reflect on the reverse case—a mode of agency in which individuals identify themselves as part of a particular social group, and for group members, there is no reference to the traditional liberal ideals of self and of action that I have argued to be so problematic. Sarah Hoagland offers such a case in her discussion of female agency and lesbian ethics. Although Hoagland’s discussion seems tangential to thinking about modes of agency for HIV positive women attempting to navigate various aspects of the Canadian health care system, her analysis is helpful for understanding the role that oppositional norms and references play in determining the courses of action that are available to individuals grouped according to particular social identities. Thinking from within lesbian lives, Hoagland argues that a radically different mode of female agency is possible. “In lesbian lives,” Hoagland writes, “we find that choice is creation, not sacrifice.” Negative agency, on the other hand, does relate to actions that are a form of sacrifice or pressed choice. The alternate view of female agency that Hoagland offers is possible specifically because it develops independently of the norms, expectations and sacrifices demanded by heterosexuality (Hoagland 1992, 198). Modes of female agency that exist within the framework provided by heterosexuality, in contrast, are oppositional to masculine modes of agency—from femininity we get dependence and manipulation, from masculinity, independence and domination. In contrast to both of these, agency within lesbian lives is within the context of a radically different community; it is decidedly collective (199).

The “economy of the Same” is a term employed by a number of feminist theorists, notably Rosi Braidotti, Rosalyn Diprose and Margrit Shildrick. The phrase refers to the exclusionary role of oppositional binaries, in which the disavowed term of the binary is translated as an absence. Diprose writes, for example, that “sexed bodies are constituted within an economy of representation of sexual difference which limits possibilities for women” (Diprose 1994). For a good explanation of how this term, particularly in relation to sexual difference and how corporeal feminist theory analyzes the Cartesian, disembodied cogito, see Bray and Colebrook 1998.

Margrit Shildrick makes this point when she discusses contemporary feminist approaches to autonomy, which emphasize the significance of relational and non-exclusionary accounts of autonomy. In many ways, I am rehearsing Shildrick’s concern that what needs to happen is a disruption of the privileged concepts themselves. See Shildrick 2008, 31-32.

This point comes up in their discussion of compliance—Thaler and Sunstein write that health care providers and pharmaceutical companies can opt to respectively prescribe and manufacture medications in such as way that it is less likely for a person to forget their pills (e.g. if they are taken once each day or packaged in such a way that “days off” of medications are placebo pills, so that one doesn’t have to remember which day to take a pill and which day to refrain from taking it). See Thaler and Sunstein 2008, 91-92. This is fine and good for a person always wants to take the medication, but it presumes that medication-taking is a private affair, once the pills are properly packaged and the prescribing is conducive
to remembering them. It doesn’t give any attention to what meanings might be associated with the medication, or how those meanings might change under various day-to-day circumstances.


Stacy Pigg has made this point, describing that within colonial projects of knowledge and expertise, supposedly universal standards of affluent Western nations are pitted against so-called “local beliefs,” setting the former apart from the latter as simultaneously “modern” and value neutral (Pigg, personal conversation).

For a discussion of how this issue applies to Foucault’s critique of Kantian autonomy, see Allen 2008, especially “Concluding Reflections.”

Note that I am not advancing this argument. I do not actually agree with the view that sex work is inherently demeaning or that paying for the use of women’s bodily capacities is always alienating (though there may be circumstances in which a transaction may be problematic).

On the flip side, social movements that attempt to reduce the incidence of drug-related harm (e.g. “harm reduction” movements) would be absolutely ineffective if it were not the case that policies can often generate the harm they are meant to resolve. Infectious diseases can and do occur with injection drug use, but this often has to do with the conditions under which someone injects (a scarcity of needles requires needle sharing, limited supplies means using dirty water, collapsed veins sometimes from rushed injections to avoid police) and not injection per se.

It is beyond the scope of this work to give a well-developed discussion of harm reduction policy and offer critically informed suggestions as to what appropriate drug policy and regulation might look like. That said, I will assert that dissuasive or discouraging policies *as they currently exist* make drug use more harmful than less, especially when we consider the effects of drug policy that enhance rather than avoid criminalizing those with problematic substance use. The obvious issue here is that drug addiction and its treatment, regardless of how embedded in medical discourses it might be, is constructed as a political condition, given the illicit status of the chemical compounds in question (Fraser and Valentine 2008, 7). Regulations and policies at the government level vary greatly, as do experiences within the operational cultures of substitution therapy and detox programs, often according to the political and economic backdrop within which they are situated. With methadone, for example, treatment guidelines are constructed such that patients can be subject to the “best interest” judgment of health care providers; substitution with methadone often “involves daily pick up and can entail conflict, humiliation, long periods of waiting and regular intrusion on privacy” (ibid).

An appropriate approach would certainly include a more historically and economically contextualized understanding of how addiction is constructed as a social problem, while logistically speaking, put less emphasis on enforcement/policing and more resources toward longer-term recovery programs. Likewise, improvements in health and well-being might be made if it were the case that issues of desert, responsibility, and moral character were not so closely tied to drug use. More systematically, addiction needs to be moved out of the individualist-cognitive model it currently operates under.
Chapter Seven

1 This is, of course, an enormous undertaking. I am not suggesting that this chapter gives a full and well-articulated discussion of “the self” in contemporary philosophy or for that matter, autonomous agency. A careful discussion would span a number of monographs, not one chapter of a dissertation. What I am offering is a sketch of what would constitute the appropriate philosophical orientation to the self as well as autonomous agency, in light of the arguments I have brought forward against the liberal tradition. I have chosen to emphasize the features of these concepts that carry out the same or similar functions to those in the liberal tradition, so as to undercut the claim that, even if we agree there are problems with liberalism in practice, the idealizations serve too important a political purpose to repudiate the tradition. This claim guides the development of the chapter.

2 Medicine is, of course, but one social field in which this discussion applies. It is by no means the limit of my analysis. The general structure and approach offered by my analysis therefore extends to the other domains and functions of autonomy, for example in politics and law.

3 I note also that autonomy is also celebrated as a liberal ideal insofar as it is thought to advance pluralism. The presence of multiple conceptions of good are seen as a wider social benefit of the promotion of autonomy.

4 As Friedman describes, in her analysis of mainstream conceptions of autonomy, the accounts given by Gerald Dworkin, Thomas E. Hill and Joel Feinberg (among others) all recognizing the significance of the social; none could really be called individualist. Dworkin, for instance, views autonomy as being about giving meaning to one’s life and acting on values and preferences that have been arrived at in a way that is free from manipulation and coercion. These are features of autonomy that require a certain kind of conducive social context (Friedman 1997, 48). Hill’s view allows for autonomous agents to accept advice, sacrifice for others’ interests, and acknowledge one’s dependence on others (49). And for as much as Feinberg emphasizes the virtues of self-reliance, self-identity and self-creation, his explication recognizes that humans are social animals and that, developmentally, autonomy is only possible when the habits of self-reflection are “implanted” from childhood on (ibid). Friedman also lists a number of other views that emphasize how institutions foster and develop autonomy, through the socialization of persons as choosers (51).

Looking at a swath of mainstream autonomy literature, she concludes that the feminist concerns about individualism are somewhat misplaced. To some extent, I agree with this claim, but would suggest that the concerns with individualism will appear misplaced because the feminist accounts are often responding to their liberal counterparts on terms that fail to move discussion of the self and autonomy away from the concerns and priorities set by a liberal view.

5 This was clear in my discussion of representative works by Harry Frankfurt and Christine Korsgaard. Frankfurt, for instance, understands responsibility to be connected up with having non-alien desires—authentic desires are those that one has identified with wholeheartedly. The agent has a self-identity (i.e. is a “person”) by virtue of their identification with their effective desires. Similarly, with the brief discussion of Korsgaard, we saw how one’s actions are reflective of oneself because they are determined by one’s having chosen them; one’s reasons for action create a unified “I.”

6 A determination of external (or non-contingent) failures of autonomy, in which the application of the concept does not even seem to apply, need not be total or complete in order to construct a group identity as separate or excluded from the norms and standards of liberal autonomy. I take it that this is part of the
way in which oppressive images and figurations are often flexible enough to accommodate a variety of circumstances, while still retaining the force of the images. For a discussion of this, see Meyers 1994.

7 Marina Oshana has made this sort of argument: that mainstream conceptions of autonomy might acknowledge that social relationships and certain external social conditions might be necessary in order to realize autonomy, but this treats social relationships as causal conditions rather than taking the view that autonomy is inherently social. See Oshana 1995, 31.

8 Importantly, I think, Friedman questions whether feminists need to regard autonomy as intrinsically social (Friedman 1997, 58). This is a question that she identifies as a location for feminist theory to push the boundaries of contemporary explorations of autonomy. It is notable that in a later work on relational autonomy, Friedman gives an articulation of autonomy that is constitutively social and relational, on the grounds that agents are socially constituted. See also, Friedman 2000.

9 For both causally and constitutively social accounts of autonomy, reflection need not be overly rational and may encompass emotional and embodied dimensions of personal processes (Friedman 2000, 37; Meynell 2009).

10 I take her concerns seriously; I do not, however, take them to mean that the thing to do is to move away from worries about autonomy altogether. By pushing against the liberal humanist view of the subject and of autonomy, my empirical work seems to make it clear that it is necessary to inquire into the place of liberal conceptions of autonomy in medicine and HIV/AIDS care. As I hope to demonstrate through my discussion of relational accounts of autonomy, a different view of autonomy—one that is premised on a dialogical and intersubjective model of the subject and is relational the whole way through—will also assist with understanding the problems of non-adherence as well as their potential solutions, in health policy and clinical practice.

11 Although I have attempted to refrain from using vague and amorphous terms such as “power,” it seems as though it is impossible to do entirely, given my need to articulate the cogency of the Butler/Foucault view for reformulations of autonomy. I note here that “power” needs to be understood as (1) existing within and through action, such that it is understood as a relation and not envisioned to be a “thing” that some person or collective hangs onto, (2) being related to systems of authority, discipline, and domination, but that these are not the only ways in which power operates; power is also productive and thus taken up voluntarily by those who would be subject to it (3) the productive elements of power still retain a connection to its disciplinary modes.

12 Alternatively, semiotics is likened with the breakdown of identity and coherence, as well as with heterogeneity.

13 Maria Lugones levels this version of the “critique of the subject” in her analysis of cultural difference—Lugones describes how full citizens imagine themselves to be culturally transparent, as though “culture” is what happens to other people. This colloquial form of “culture” is often taken to be static, fixed, and separate; not worth knowing by those who are part of the dominant invisible culture, which is imagined to not be a culture at all (Lugones 1994, 461-462).

14 Mackenzie and Stoljar give a short depiction of these in their introduction to their collection, Relational Autonomy. Theorists from a wide range of perspectives tend to draw on the “critique of the subject,” which emphasizes the problematic features of the liberal account’s view of the self. Many of these issues are ones I have raised through my empirical data—the problematic way in which liberal philosophy views
the self as unified, ideally able to achieve self-mastery, self-transparent, etc. Mackenzie and Stoljar 2000, 10.

15 I will suggest that the intrinsically relational accounts need only to go further in their analyses in order to avoid the challenges I have raised. In contrast, liberal accounts of autonomy, like causally social accounts, do not have the conceptual resources to do so.

16 These might loosely be defined in terms of the capacities needed to develop and exercise self-determination; a number of feminist accounts articulate this list as including critical self-reflection, self-discovery, self-definition, as well as more externally-focused capacities such as interpersonal trust.

17 The sort of example I have in mind can be found in Denise Gestaldo’s work examining health education practices. Employing Foucault’s concept of biopower, Gestaldo argues that norms of healthy behaviour, conceived of by policy makers and governments, construct normative views of what is “good” for a population to achieve, while simultaneously constructing those who do not embody health behaviour norms as deviant. While we might think that health education is liberatory and empowering for citizens, Gestaldo’s work problematizes “empowerment” in a number of productive and fruitful ways.

18 By this, I mean to highlight how mainstream liberal accounts do not seriously address Foucault’s position that technologies of the self must be studied together with technologies of domination and “take into account the points where the techniques of the self are integrated into structures of coercion or domination” (Foucault 1993). See also, Amy Allen 2008, especially Introduction and Chapter Three.

19 See Allison Weir, Sacrificial Logics, for an in-depth analysis of the view that identity is necessarily repressive of difference. Weir identifies two models of identity: those aligned with Lacan, in which the is a stoic/tragic model of the self means that the repression must be accepted (as a loss); and those aligned with Derrida and Butler, which Weir refers to as a “skeptical” model, that argues that there is no basis for the differentiation between repressive and non-repressive forms of identity, given that identity is only possible through subjection, which occurs within and through disciplinary norms. See Weir 1996, especially chapters five and six.

20 One of the most profound implications of Butler’s work for feminist theory has been the insight that her analysis provides into the phenomenon whereby it is quite common for those who are subordinated to be attached to oppressive norms and institutions, even when they “see” these norms for what they are. This issue has raised the ire of feminists particularly as it relates to norms of femininity. For as solid as the critique is, even those who embrace the critique often engage in practice that can be said to instantiate the norms themselves. See Bartky, Psychological Oppression (2005) and Bartky, Sympathy and Solidarity (2002); for a discussion of the latter, see Allen 2008, 73-74.

21 This is the foundation of Foucault’s reputation as an anti-humanist responsible for the postmodernist “death of man.”

22 My parroting of Butler’s discussion of materiality is purposive. In many ways, I am offering an analysis of the construction of non-adherence and social identity that is parallel to her discussion of materialization:

These material positivities appear outside discourse and power, as its incontestable referents, its transcendental signified. But this appearance is precisely the moment in which the power/discourse regime is most fully dissimulated and most insidiously effective. When this material effect is taken as an epistemological point of departure, a sine qua non of some political argumentation, this is a move of empirical foundationalism that, in accepting the constituted
effect as a primary given, successfully buries and masks the genealogy of power relations by which it is constituted. (Butler 1993, 35)

My analysis of the looping effects and HIV-related pathologies suggests that the “healthy” bodies of rational autonomous agents are those that appear outside of discourse and power, just as the liberal normative framework itself does.

23 Contending with these two challenges leads me to address both of definitions of “relational” that Friedman associated with constitutively relational accounts—that of a relational “self,” and that of relationality per se.

24 Weir writes that self-identity requires the capacity to “sustain and in some sense reconcile multiple and often conflicting identities and to understand, criticize, and reconcile multiple and often conflicting interpretations of those identities.” See Weir 1996, 186.

25 Coherence may well be superficial. Weir states that although individuals must be able to organize their diverse identities into “some sort of meaningful narrative or constellation” (Weir 1996, 187), she argues that the practical capacity to discover, define and commit to particular meaning is a resolution of conflict into a more general meaning that remains flexible and open (ibid, my emphasis). Weir emphasizes that one must detach in order to reflect on particular meanings and bring them into the fold of a more general set of meanings (187-189). Sarah Buss offers insight into how this detachment belies the emphasis that the liberal tradition places on coherence of beliefs for rational agency. If reflection on a belief requires that one dissociate oneself from the particular mental state, surely integrity doesn’t depend on maintaining an especially coherent set of beliefs at all times. And if coherence comes in degrees, then some incoherence cannot be a threat to rational agency (Buss 2006, 314-315). The question of course is where the limits of incoherence are, for integrity and identity.

26 For a discussion of some of the epistemic, moral, and political implications of dialogical models, see Lorraine Code’s description of ecological thinking (Code 2006). Code conceives of an ecological subject as one that exists in dialogue with other subjects, communities, and social-political-academic discourses; this is a situated protagonist who is internally and externally interdependent, situated within locational possibilities and limitations (Code 2006, 3-5).

27 With respect to this issue, Weir relies on Julia Kristeva’s understanding of language as a dialectic between structure and practice and envisions intersubjectivity as providing the possibility of non-repressive aspects of identity, insofar as it theorizes the instability of meanings that are generated within and through social symbolic interaction (Weir 1996, 146). The intersubjective construction of the self refers to the construction of the self by way of participation in particular communities, institutions and systems of meaning (185).

28 This should not be taken as a glorification of identities of difference and the conditions of oppression. I include this as a cautionary note against the excesses of identity politics, which have a tendency toward essentialism. For a short but insightful discussion of this, see Bat Ami Bar On 1993.

29 It is on the basis of her discussion of possibilities of alienation from normative structures that Weir is able to theorize a “capacity for abstraction, for detachment, for critique, which is not opposed to but continuous with, and in fact constitutive of, participation” (Weir 1996, 190).

30 This was Butler’s major contribution to understanding the psychic aspects of power that I am arguing needs to be contended with by any account of autonomy.
Allen argues that the temporal and dynamic aspects of social relationships allow for mutual recognition as a possibility within social life, however fleeting (Allen 2008, 91).

See also, Taylor 1985; Benhabib 1999.

This is not meant to suggest that autonomy is about language and not practice—the term discourse is suggestive of the two and their interrelationship with one another.

For a related discussion see Allen 2008, 180

Christman cites Mackenzie and Stoljar’s discussion of metaphysical critique of autonomy in making this point. Mackenzie and Stoljar argue that metaphysical critiques of autonomy are unfounded; they claim that there is nothing about anti-individualism (which might be accepted on a variety of different grounds) that warrants a rejection of autonomy (Mackenzie and Stoljar 2000, 8; my emphasis). They make this argument in order to suggest that “to rehabilitate individual autonomy, does not entail rehabilitating individualistic autonomy” (ibid). As I read their discussion, in light of their claim that their purpose in editing the Relational Autonomy collection is to reconfigure and reconceptualize individual autonomy as “relational” as well as their inclusion and tacit endorsement of a number of constitutively social accounts of autonomy in the volume, it seems misplaced to suppose (as Christman does) that their use of the term “individual autonomy” is indicative of a rejection of constitutively relational accounts. Individual autonomy seems instead to refer here to personal autonomy and is not meant to indicate that constitutively social accounts of autonomy are mistaken, as Christman seems to take them to mean.

Further to this point, Christman cites Allison Weir in arguing that there is a logical gap between rejecting metaphysical individualism in the realm of the self and embracing a metaphysically relational conception of the self. I note that although Weir is working from a pragmatic/political view of identity in order to motivate her analysis of identity, identification and critical reflection, she is still working from a dialogical model of the self that recognizes the cogency of Butler’s critique of the subject.

The subject-object social symbolic order that is embedded in traditional liberal thought construes others as ours (objects) or ourselves (as in a universal subject). The monological mode of reasoning is understood as an appropriation, either by a lack of differentiation between subjects, or the transformation of other into object, to be seized consumed (Irigaray 2004, 5; 23). This contrasts with a dialogical order, in which subject and subject come toward one another with an understanding of alterity and the acknowledgment of their irreducibility—a relation with the other as such (Irigaray 2004, 25).

I make this point because Allen’s analysis of power and validity is directed toward Habermas’ dialogical model of communicative action—as I see it, the force of her claims is even more cogent for the troubles generated by a monological model. Her point is that participation in social relationships and establishing intersubjective agreement cannot be enough to elevate the status of normative judgments from belief to universal fact. A monological worldview that attempts to bring in the social as a background condition, but continue to try and isolate its own normative structure from critique will face the same problems as Allen lays out for Habermas.

In the Hegelian dialectic, being an “I” is a reflexive move that relies on the Other; Butler worries about this reliance as a source of vulnerability to subordination. Luce Irigaray, however, argues that so long as the “you” is irreducible and the limits of knowledge and perceptibility of the other appreciated, it is possible to avoid the problematic aspects of vulnerability (Irigaray 2004, 24-25).
This characterization comes from Scott Anderson. Autonomous agents are considered to be responsible for their actions and the effects of these (either known or reasonably predictable) because those actions are self-determined. But to be determined responsible for something is to have been presumed autonomous in your having done it.

Although she doesn’t cite a debate between liberal and postmodernist theories, Susan Wendell gives a good description of the challenge between agency and causal pictures. See Wendell 1990.

Wendell cites Marilyn Frye’s analysis of “blaming the victim,” which I take to be a good example of how more apt judgments of responsibility can come from a relational view of the self and of autonomous agency. For example, focusing attention on the individual characteristics of victims as causal factors in an event or outcome and away from their situatedness within a given context, or others’ responsibilities to them, has a tendency to reproduce oppressive structures and their effects. In the example of educational underachievement that Frye gives, an emphasis on measuring and acting on girls’ fears of success orient the analysis of the problem toward the characteristics of the victim, rather than seeing how the qualities of other agents (both individual and collective) and the relationships between these agent may play more substantive role in this outcome. I note that this analysis is also something of a counter-example to Sunstein’s discussion of racialized norms and educational underachievement discussed in chapter six. His analysis of the need to change social norms (rather than interrogating whether the educational system or the structuring of wider life opportunities outside of the school system) focuses the attention on the problematic norms perpetuated within an already maligned social group. See Wendell 1990, 20; and Frye 1985.

It should be noted here that the liberal account cannot simply help itself to such a view of the self, given the commitment to the ideals of unification, transparency, universality, and a monological engagement with the world, all of which treat the self as a kind of substrate or ontological entity.

The evidentiary basis of outreach in the United States is primarily from the National Institute on Drug Abuse (NIDA); outreach programs are a major component of AIDS intervention and research launched under NIDA. Outreach is described within the multisite intervention studies as a “proven approach for reaching hidden populations of IDUs” and as having “theoretically effective elements of behaviour change models, especially communications theory about credible messengers and health behaviour theory about self-perceptions of vulnerability” (Coyle et al. 1998, 20-21). The relationship between the historical aspects of outreach programs in HIV/AIDS and health behaviour models, which I have argued are underpinned by rational actor models and liberal frameworks of autonomous agency, is noteworthy.

In contrast to an instituted imaginary, which carries the normative social meanings, customs, expectations, prohibitions, values, etc. of a given society, an instituting imaginary “is the critical-creative activity of a society that exhibits its autonomy in its capacity to put itself to question” (Code 2006, 30-31). Code refers to instituting imaginaries as counterpossibilities—images that destabilize social structure and initiate new meanings (31).

Similarly, Stuart Murray’s work in bioethics, on genomic technologies and the understanding of the self bequeathed by liberal humanism, suggests that a better understanding of “technologies of the self” may help us to imagine subjects in a different way, ones “who might enter the discourse of its own subjectivation.” I read this as a more participatory and potentially (though by no means necessarily) emancipatory mode of engagement with the world. See Murray 2007.
Conclusion

1 I have, for instance, offered to take different participants to medical appointments—women are unable to attend because of drug use or drug dealing issues apologize for giving me “the run-around,” one women referring to herself as “an asshole.” When I had said it was fine, it didn’t matter, it was her choice, she replied, “no really, I’m an asshole.” While one could look at this as a rhetorical device to prevent an angry reaction from a support person, the participants’ familiarity and relationship with me makes this unlikely (i.e. I am not their physician, have never been upset with them in the past, etc.). Missy, for example, has said to me that she doesn’t like to “let me down” when I’ve offered to take her to an appointment. Outreach workers also often described to me that women have “a lot of shame” around drug use, particularly when it interferes with their using health services.

2 One of the first world-wide public health strategies to explicitly engage with human rights took place in the late 1980’s, under the direction of Jonathon Mann (See Mann 1997). Human rights have been inextricably linked to the AIDS pandemic and to HIV/AIDS public health policy. For example, civil liberties were paramount in initial responses to the epidemic; women’s rights regarding sexuality and reproduction have become a prominent feature of HIV discourse—the XVI International AIDS meetings and those that have followed reflect this trend; in 2007, the Lancet ran a four-part series of essays examining the combination of health and human rights.

3 This program is titled “Seek and Treat to Optimize Prevention of HIV & AIDS.” The program is based on empirical research indicating that patients with suppressed viral loads are less likely to transmit HIV to uninfected partners; the expansion of ART to HIV-infected community members in the Downtown Eastside is expected to lower what has been termed the “community” viral load and thereby diminish the incidence of HIV in the neighbourhood. See Montaner et al. 2006; Anema et al., 2008; Lima et al., 2008; and “Antiretroviral treatment for prevention,” UNAIDS 2009.

4 When Luce Irigaray talks about feminine subjectivity, for example, she explains how in the Western tradition, “the other is always seen as the other of the same, the other of the subject itself…” .See Irigaray and Guynn 1995.
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Department and Hospital Use by Injection Drug Users in Canada. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*.


UNAIDS 2009. Antiretroviral Treatment for Prevention. UNAIDS.


ETHICS CERTIFICATE OF EXPEDITED APPROVAL: AMENDMENT

PRINCIPAL INVESTIGATOR: Mark W. Tyndall
DEPARTMENT: UBC/Medicine, Faculty of Medicine, Department of Infectious Diseases
UBC-PHC REB NUMBER: H07-00034

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children's and Women's Health Centre of BC (incl. Sunny Hill)</td>
<td>Children's and Women's Health Centre of BC (incl. Sunny Hill)</td>
</tr>
<tr>
<td>Providence Health Care</td>
<td>St. Paul's Hospital</td>
</tr>
<tr>
<td>Vancouver Coastal Health (VCHRI/VCHA)</td>
<td>Vancouver Community</td>
</tr>
</tbody>
</table>

Other locations where the research will be conducted:

Research sites will depend on participants recruited. We have identified three main clinics that women living and working in the downtown eastside (DTES) use regularly - these are Downtown Community Health Centre, Pender Clinic and Vancouver Native Health. Participant-observation will take place in public areas of these clinical settings (e.g. clinic waiting rooms) as well as during the provision of healthcare services (with mutual consent from patients and healthcare providers). Interviews with women participants will take place at a location of their choosing. Interviews with healthcare provider participants may take place at clinic sites (e.g. physicians’ offices in the named clinics ). St. Paul's Hospital Emergency Department has been contacted for collaboration, and Oak Tree Clinic at BC Women's Hospital is included in the application. Participant observation will take place in the main areas of these locations (e.g. waiting room, triage desk). For key informant interviews, participants will be asked to choose a time, date, and location that conveniences them (e.g. nearby coffee shop).
<table>
<thead>
<tr>
<th><strong>CO-INVESTIGATOR(S):</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Susan G Berkhout</td>
</tr>
<tr>
<td>Neora Pick</td>
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<th><strong>SPONSORING AGENCIES:</strong></th>
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<td>Michael Smith Foundation for Health Research</td>
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<th><strong>PROJECT TITLE:</strong></th>
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<tr>
<td>Institutional Resources and Risks: Exploring the Social Structural Dynamics of the Health of Women in Vancouver's Survival Sex Trade through Clinical Ethnography</td>
</tr>
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</table>

REMINDER: The current UBC-PHC REB approval for this study expires: 27 August 2008
Appendix 2: Methodological Information

In an effort to provide additional detail to the research methodology, I have constructed two tables outlining the research sites, participants, and interviews that took place in each location. I spent a great deal more time with two women participants in particular—Missy and Carly—and amongst the health care providers, the number of hours of participant observation with the home care nursing team was substantially greater than within the community clinic locations. The analysis that I offer in the dissertation reflects these differences, and I have taken care to ensure that findings were not generalized or insensitive to the particularities of the context within which the information was gathered.

Participant Observation

<table>
<thead>
<tr>
<th>Location</th>
<th>Participant Observation</th>
<th>Approximate Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Clinic Setting</td>
<td>Outreach Services</td>
<td>5 hours</td>
</tr>
<tr>
<td></td>
<td>Physician Care (General and with 1 Participant)</td>
<td>20 hours</td>
</tr>
<tr>
<td></td>
<td>Drop-in</td>
<td>6 hours</td>
</tr>
<tr>
<td></td>
<td>HIV Nursing (General)</td>
<td>3 hours</td>
</tr>
<tr>
<td></td>
<td>Other (e.g., Staff Meetings)</td>
<td>24 hours</td>
</tr>
<tr>
<td>Not-for-Profit Clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RHA-Funded Clinic</td>
<td>Nursing</td>
<td>5 hours</td>
</tr>
<tr>
<td></td>
<td>Physician Care (General and with 1 Participant)</td>
<td>17 hours</td>
</tr>
<tr>
<td></td>
<td>Directly Observed Therapy program</td>
<td>18 hours</td>
</tr>
<tr>
<td></td>
<td>Women-only Drop-in</td>
<td>30 hours</td>
</tr>
<tr>
<td>Specialist Clinic</td>
<td>Waiting Area</td>
<td>4 hours</td>
</tr>
<tr>
<td></td>
<td>Staff Meetings</td>
<td>18 hours</td>
</tr>
<tr>
<td></td>
<td>Clinic (With 1 Participant)</td>
<td>6 hours</td>
</tr>
<tr>
<td>Hospital</td>
<td></td>
<td>60 hours</td>
</tr>
<tr>
<td>Home Care Nursing</td>
<td></td>
<td>60 hours</td>
</tr>
<tr>
<td>Community (non-medical)</td>
<td>Women Study Participants (7)</td>
<td>180 hours</td>
</tr>
</tbody>
</table>
## Interviews

<table>
<thead>
<tr>
<th>Informant</th>
<th>Number of Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Women Participants</strong></td>
<td></td>
</tr>
<tr>
<td>(7)</td>
<td></td>
</tr>
<tr>
<td>Missy</td>
<td>6 + 3 Follow-up</td>
</tr>
<tr>
<td>Carly</td>
<td>6 + 2 Follow-up</td>
</tr>
<tr>
<td>Dee</td>
<td>2 + 1 Follow-up</td>
</tr>
<tr>
<td>Tina</td>
<td>2</td>
</tr>
<tr>
<td>Pink</td>
<td>3 + 1 Follow-up</td>
</tr>
<tr>
<td>Angel</td>
<td>2</td>
</tr>
<tr>
<td>Pearl</td>
<td>2</td>
</tr>
<tr>
<td><strong>Physicians</strong></td>
<td></td>
</tr>
<tr>
<td>Addictions</td>
<td>1</td>
</tr>
<tr>
<td>Primary Care</td>
<td>6</td>
</tr>
<tr>
<td>Infectious Disease</td>
<td>2</td>
</tr>
<tr>
<td>Pediatrics</td>
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<tr>
<td><strong>Nurses</strong></td>
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<tr>
<td>Home Care</td>
<td>15</td>
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<tr>
<td>Specialist Clinic</td>
<td>1</td>
</tr>
<tr>
<td><strong>Nurse Case Managers</strong></td>
<td></td>
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<td>Community Clinic</td>
<td>3</td>
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<tr>
<td><strong>Social Work/Outreach</strong></td>
<td></td>
</tr>
<tr>
<td>Clinic</td>
<td>3</td>
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<tr>
<td>Hospital</td>
<td>1</td>
</tr>
<tr>
<td><strong>HIV Researchers</strong></td>
<td>5</td>
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<tr>
<td><strong>Health Administrators</strong></td>
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